THE CLASSIFICATION AND MEASUREMENT OF DISABLEMENT

by

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Note to Readers

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CHAPTER ONE

DEFINING TERMS RELATING TO DISEASE CONSEQUENCES

A Consistent Terminology

There have been several calls in recent years for a more exact use than is customary of certain terms commonly used in health and medicine. Probably the best example of such a call in Britain is that made by R. G. Mitchell, the editor of 'Developmental Medicine and Child Neurology'. In 1973 he drew attention to some of the very practical reasons why doctors should devote considerable care to the way they employ the many semi-technical terms which they hold in common with other health professionals.

It seems that out of deference to one another, and even to 'lay' groups with an interest in medicine and health, health professionals have tended to use these terms very loosely indeed. How Mitchell saw the situation and which terms he is referring to is shown in the following quotation:

> 'Precision in the use of medical terms is sometimes disparaged as mere pedantry. Nevertheless it is important that words used by doctors should be carefully defined, in order to allow intelligible communications with one another and with associated professions. Precise terminology is also necessary for efficient administration, as in identifying those who qualify for help provided for specific purposes. A case in point is the Family Fund established by the British Government as direct aid to the families of children with very severe handicap of congenital origin. But what constitutes 'handicap', what is 'very severe' and what does 'congenital' mean? If these and other key words such as 'malformation', 'deformity' and 'disability' are not defined, money and services may not be directed where they are most needed and may be used for purposes for which they were not intended'. (Mitchell, 1973)

Inevitably, the Americans have been there before us, and Mitchell's plea for careful definition could serve to reinforce Nagi's description, written

in 1969, of inconsistency in the use by doctors and other health professionals of certain key words within rehabilitation:

> ''Several attempts have been made towards a much needed clarification of concepts surrounding the phenomenon of disability. A brief review of the literature reveals a great deal of inconsistency in the use of terms such as illness, sickness, impairment, handicap and disability. For example, although illness is defined by some as 'any symptom or syndrome that the American medical profession, at the present time, generally accepts as evidence of ill health', it is considered by others to be 'a social entity or status defined in terms of social functioning'. And though disability is described at times as 'more particularly a medical condition', the evaluation of which 'is an administrative not medical responsibility and function'. Regardless of the utility of the distinctions available in the literature to the purposes for which they were made, the picture remains one of semantic confusion''. (Nagi, 1969, p.10).

Reasons for confusion

A closer examination of the two quotations above reveals that the problems which Mitchell and Nagi were confronting were not quite identical. Mitchell was not merely echoing Nagi, he was mainly concerned about the misunderstandings which often arise between professionals even though they have the same ends in view. Professionals are not always aware when members of other professions are using terms with a frame of reference different enough to imply that they inevitably carry a somewhat different meaning. To give a very simple example, a certain group of 'disabled' persons may be regarded primarily as people recoving from stroke by the doctor, but they may be regarded primarily as applicants for invalidity benefit by the civil servant.

Nagi was writing against the background of a clash which is more than a mere matter of words. He was referring to a conflict between values and meanings of which the professionals on both sides were very much aware.

The American Medical Profession and 'others' - medical sociologists perhaps - employed the same words but deliberately ascribed a different set of meanings to them so that rivalry ensued. Yet both groups could claim that they were employing the words correctly, for 'disability', as Nagi (1965) has suggested, has significance in the real world as both a health and a social problem. It may be partly as a result of the conflict which arises between health and social perspectives that 'ordinary' people, who are not doctors, sociologists or linguistic philosophers, often construe different uses of the same terms as conceptual confusion.

More conventional theories of how conceptual confusion has arisen can be constructed. An obvious source of misunderstanding is the use of medical and health terms by lay-people and doctors alike when they attempt to communicate with one another. There is bound to be some degree of looseness in everyday speech and writing in this situation. It is easier to write about 'physically handicapped people' than to use a more exact but cumbersome phrase such as 'people who have handicaps which have arisen because they have disabilities in consequence of an impairment in the functioning of some particular organ'. In speech, such an attempt at circumlocutory phraseology would obviously be quite impracticable.

Terminological confusion a general phenomenon

Another call for a rationalisation of terminology, this time within psychology, provides yet another explanation for confusion - that careless professionals breed even more careless students. Thus it has recently been suggested by Morrison (1979) that a suitable way of celebrating the centenary of Wundt's psychological laboratory would be to purge psychology of those besetting faults which still prevent its general recognition as a science. One of these faults, not surprisingly, is imprecision is the use

of important terms: perception, instinct, intelligence, ability, etc. Morrison contrasts psychology with physics. Physics either has taken words in common use and redefined them more precisely or has borrowed terms from the classical languages and coined neologisms. Psychology, it appears, has been just as adept as physics at the latter process, but distinctly falters when undertaking the former:

> '... far from treating such terms as perception ... and so on, as physicists treat energy, some psychologists occasionally use them so loosely as to make it difficult for students, especially beginners and those taking psychology as ancillary to some other subject (eg education), to grasp what exactly the terms denote .... Does any other would-be science treat its tyros so scurvily?'

The answer to this question is, unfortunately, a resounding affirmative. The practitioners of medicine and health, though they have been rather more ambivalent, or at least less concerned, than psychologists about acquiring for their discipline the designation of 'science', have been equally heedless of the difficulties of their novices and of their own use of appropriate terminology.

However, whatever the source of the imprecision in use of words - whether it is carelessness, conflict or conspiracy - exhortations to self-improvement, provided they are not repeated too often, are probably essential and sometimes are not without effect. Thus Jones et al. (1976) have remarked that information on the relationship between the processes of medical care and what they refer to as 'patient outcomes' depends on the development of a standard terminology for describing the health status of chronically ill and disabled patients. They pointed out that it was more that 20 years ago that the Commission on Chronic Illness in the USA recommended 'the adoption and widespread use of comparable terminology ...

[as] essential steps toward improving the usefulness and meaning of data collected and analysed for various purposes by health organisations and by persons who investigate needs and resources for care of long-term illness' (Commission on Chronic Illness, 1956).

Experience at two conferences

More recently, at a seminar organised by the United Nations in Warsaw on the subject of the contribution of social security and social services to the rehabilitation of the disabled, the addresses of three of the main speakers may have seemed rather dull because they found it essential to spend about a third of their time defining the terms and concepts they were using (United Nations European Social Development Programme, 1973). Yet, in view of the widely different backgrounds of the participants, such definition and explanation was essential, and the experience of participants at a rather similar kind of conference with British participants only would suggest that it is unlikely that the Warsaw conference would have been as enlightening without the careful definition and explanation that took place.

This British conference, sponsored by the Social Science Research Council, took as its subject 'The Cost of Human Impairment' (Lees and Shaw, 1974). The conference was undoubtedly successful in that everyone was better informed afterwards, but it seems that what is referred to as 'a secondary form of ambiguity' bedevilled the conference even at the planning stage. This particular problem was that of the definition of terms, and the editors of the published report of the conference express its ramifications so clearly that it seems worth quoting them at length.

'When we first encountered it this [problem] seemed no more than a minor difficulty, which could be resolved in Humpty Dumpty fashion by people defining and using the words 'impairment', 'disability' and 'handicap' as they pleased. We don't want to waste time arguing over terminology, we said; it doesn't matter if Professor X uses the terms interchangeably while Dr Y attaches specific meaning to each one, so long as we know they are doing this. However, it transpired that these definitions can be very important, and, indeed, reflect one of the most fundamental conceptual differences of approach to the whole problem of disability that emerged at the conference .... Doherty, Lees and Culyer, writing from the traditional economists' viewpoint, were able to treat impairment, disability and handicap as one and the same thing, since the economist is dealing with physical impairment as a general class of effects which give rise to those costs which are the real focus of his interest .... Garrad's study, which was aimed at an eventual assessment of the provision of health and social services, required a precise measurement of the kinds of physical condition which would necessitate different kinds of help. For this sort of fine-grained work which is used to classify individual cases rather than broad cases, the question of functional ability to perform different tasks is crucial. Hence her separation [of chronic disability experience] into two distinct categories: impairment ... [and] disability'. (ibid p4).

Lees and Shaw go on to point out that problems of definition and classification recurred fairly regularly throughout the discussions and that one issue that might have appeared to be merely 'a case of semantic nicety' - whether 'disability' is best defined by the disabled themselves or by professionals - turned out to have a very practical bearing on actual costs: 'The more people can be given some incentive to reject the invalid role and maintain independence, the less will be their overall support cost'. (ibid p5).

Careful definition of terms, then, is obviously important. At the same time, it seems that definition of terms by itself is rarely enough for a

complete specification of meaning. Kaplan (1955) has discussed this matter. He has pointed out that a particular definition is invariably concerned with the outcome of the processes of inquiry and meaning at some particular stage. A definition by itself can indicate little about any modifications of meanings which may have taken place over the years; it will only indicate meaning at a particular moment in time. Putting this more generally, it may be suggested that a particular concept often has various meanings in different contexts; meanings which are not related to one another as logical equivalents, but which empirically coincide to a greater or lesser degree.

The search for totally adequate definitions seems, therefore, doomed to failure. Yet a search of some kind must go on, for it seems obvious in the light of Lees' and Shaw's editorial introduction quoted above that, even if its exercise has to be repeated periodically, the careful definition of key terms, including 'health' itself, is central to the proper understanding of health-care institutions and policy. However, this kind of work needs doing well, if it is done at all. Kelman (1975) evidently feels that health professionals are all too willing to accept definitions which are less than satisfactory. He suggests that the World Health Organisation's definition of health as '... a complete state of physical, mental and social well-being, not merely the absence of disease ...' fails because it is utopian and ahistorical. It neither incorporates the limitations to the attainment of health nor accurately depicts health behaviour in contemporary society. Kelman would prefer definitions of health which describe 'a situation in which for a given individual the experience of well-being coincides with the ability to fulfil his or her social role', together with a critical historical

analysis of the context in which that role is to be performed. A 'good' definition of health in Kelman's terms will, therefore, vary according to time and society, ie to context. Hence, in defining health in a particular way, one is forced into implicitly stating a view of that context. Refusing to define may be tantamount to attempting to abdicate from having a view at all.

Types of definition of disability

As with health, so obviously with one of its antonyms, 'disability'. Disability is an excellent example of a term whose definition will quite properly vary according to its context. If what, in Kelman's terms, are some rather ahistorical micro-contexts are looked at first, we find that Krause (1976) has made a useful distinction between several definitions of disability in which each definition is distinguished by its relationship to the interests of the group of professionals which is responsible for its formulation. He suggested that the concept of disability is best portrayed by three such professionally oriented definitions, portraying the following main types of disability experience:

i. 'biopsychological disability': in which the definition of terms is primarily undertaken by those qualified to judge physical and mental functioning by generally accepted standards. (Biological or medical disability would seem adequate alternative titles for this kind of disability).

ii. 'social role disability': in which the disability is relative to the demands made on the individual by society. (Krause suggests that, in constructing definitions relating to this kind of disability, both the physician and the sociologist will have a major role, since this kind of disability will invariably have a mixture of medical and social antecedents).

iii. 'legal disability': in which the definitions, though they may be based on medical and social criteria, have the force of law. (Both administrators and lawyers will have a major part to play in formulating definitions of this kind).

Definitions in Social Security

Krause has therefore provided a simple classification of definitions of disability based on the context in which particular professional groups operate. He pointed out that there is a progression in this classification, i.e. the movement from 'biopsychological' through 'social role' to 'legal' definition also involves a movement from science to politics and a movement from objectivity to arbitrariness. Krause's main purpose in drawing attention to these connnections between the three types of definition was that it enabled him to develop a thesis that treating legal definitions as if they were wholly scientific and objective has given rise to many problems in social security legislation. He discusses some of these in the context of the United States' Social Security programme of the 1960's. For example, under the legislation then in force, a majority of the disabled, as defined by medical criteria, were not receiving benefits because

> 'The laws making someone eligible for Social Security only if he or she worked at stable jobs in covered workplaces for a five-year period, neatly disqualified many houseworkers, farmworkers and marginally employed people who needed the protection the most. Not accidentally, but because of lobbying by agricultural interests, the same individuals were not covered by most workmen's compensation coverage laws .... Being outside the laws, these individuals cannot legally get compensation when they are injured at work. For these people, there is no legal definition of disability, with accompanying rights and funds for compensation and rehabilitation.' (op. cit., p.205).

Some commentators, eg Ogus and Barendt (1978), suggest that the same kind of problem in a less acute form can arise within British Social Security practice. Thus there is apparently considerable resistance on the part of the Trades Unions to any reduction in the present preferential treatment of those disabled at work over those disabled by, for instance, accidents in the home.

Classification of definitions

What seems to be, at first sight, a more 'scientific' and, therefore, less controversial approach to the classification of definitions of disability and related concepts is to use the purposes that the definition are intended to serve as a basis for their classification. However, before we can classify, we have to compose some definitions which are classifiable.

First, we might well begin with a 'dictionary' definition of disability: eg. 'the thing, want, that prevents one doing something; especially physical incapacity caused by injury or disease'. This, like most dictionary definitions, is quite general. It has no explicit reference to purpose nor would it be what Kelman (1975) regards as a particularly useful definition, being ahistorical, apolitical, etc. Rather, it is what Jazairi (1976) has called a 'generic' or 'global' definition. Other global definitions can be used as a starting point and Jazairi gives two examples.

His first example is the 'old' concept of morbidity as used by the World Health Organisation: 'any departure, subjective or objective, from a state of physiological well-being'. However, he rejects this definition as a starting point in favour of one of his own devising: 'all limitations of the individual's activities due to illness or injury'.

The next stage in framing definitions relevant to the purpose for which they are used is illustrated well by work done by Slater et al. (1974). Starting from WHO global definitions of disability they formulated a 'working' definition:

> 'Disability is an existing limitation in one or more activities which in accordance with the subject's age, sex and normative social role are generally accepted as essential, basic components of daily living'.

This definition is more specific about purpose because it provides information about the kind of 'indicators' that will be used to form indices or scales that can be used to measure the concept it defines.

Slater and his colleagues also point out that the definition above has other advantages. In particular, it meets the need for instrumentation because when disability is defined in terms of limitation of activity, there is a distinct possibility of treating it as a continuous variable and not merely as a threshold phenomenon. In consequence, the measurement of degrees of disability is made more precise.

Operationalization of definitions

A further step in formulating definitions is 'operationalization' i.e. assigning meaning to the definition by specifying the indicators, activities or 'operations' necessary to measure its content. Slater et al. (op. cit.) suggest that as many operational definitions will be required as there are 'sources' used as bases for ascribing disability. (These 'sources' correspond quite closely to some of Krause's 'contexts' though without the time element.) They specify six sources altogether: 'subjective', 'behavioural', 'significant others', 'professional-medical', 'legal' and 'community'. To give an example: an operational 'professional-medical' definition of disability would be based on the judgement ofthe degree of the subject's disability made by a physician examining the subject. Specifying the operations in more detail, and relating them to the working definition of disability, Slater et al.'s version of a complete operational definition of professional-medical disability reads as follows:

> 'all examined subjects will be rated by the examining physician as to the expected degree of limitation in the essential basic components of daily living, the impairment to which the limitation is attributable, the prognosis for the impairment and a summary judgement of the degree of disability'.

In sum, in an operational definition, the operations defining professional-medical or any other kind of disability are clearly and exactly specified. Several operational definitions will be required, each corresponding to the context in which it will be used.

Summary

The argument of this chapter is fundamental to the remainder of this study and is therefore repeated here. It is suggested that imprecision in the use of health terms which professionals wish to use in exact senses may

have several sources, varying from 'lay' influence when the term has wide currency, to a lack of awareness that definitions need to be shaped for the purposes that they are intended to serve, though they will inevitably be influenced by social and historical forces. A need to formulate a definition even at the global level where there is no explicit reference to time and purpose does not mean that any definition taken out of the nearest dictionary will suffice for every occasion. Partly, as Kelman has suggested, 'good' definitions should facilitate the current analysis of health care institutions and policy. Partly also, as Krause would suggest, definitions are to be thought of as adequate or inadequate in terms of the context in which they are to be used. Alternatively, Slater et al.'s classification of definitions as 'global', 'working' or 'operational' seems to provide a framework by which definitions might be judged as good or not in terms of the purpose which they are intended to serve. Thus while a 'global' definition of disability is seldom sufficiently related to context to provide an adequate definition for the development of indicators, it serves for its own purpose, which is to delimit the subject under discussion. A definition which permits the development of indicators is a 'working' definition. This kind of definition must be precise enough to suggest the content of the indicators, but must not be so precise that it cannot be generalised to a variety of contexts. Finally, for application to particular contexts an operational definition is required. These are framed so that measurement can take place and so that the precise nature of any subsequent analysis of data is indicated.

Obviously, particular health professionals are concerned with definitions within a limited range of contexts and purposes. In Krause's terms these contexts

are more usually biopsychological than legal but, whatever they are, it is, as Cromwell and his co-workers (1975) have suggested, important that health professionals should not assume that a definition once laid down will do for all time. Rather professionals should from time to time take stock of the significant terms they commonly use, reassess their meanings, and determine precisely what purposes they appear to be and ought to be serving. The next two chapters especially will draw attention to recent attempts at this kind of reappraisal for terms which are used to express various aspects of disease consequences.

CHAPTER TWO

SOME CONCEPTUAL SCHEMES CENTRED ON ''DISABILITY''

Use of the term 'disability'

In a paper delivered to the Royal College of Surgeons, Townsend (1967) has listed five distinct uses of the term disability. In the order in which Townsend gives them, these meanings are:

i. an anatomical, physiological or psychological abnormality

ii. a chronic clinical condition altering or interrupting normal physiological or psychological process

iii. a functional limitation of ordinary activity

iv. a pattern of behaviour of a socially deviant kind

v. a socially defined position or status, usually of inferiority. (op. cit., pp 4-6).

Each of these meanings is quite distinct, pointing to separate contexts within which the term disability could be appropriately used. Is it possible to align these with the classifications of definitions of disability discussed in the previous chapter?

A starting point is provided by comparing the third of these meanings with Jazairi's (1976) global definition of disability: 'all limitations of the individual's activities due to illness and injury.' (supra p.10). There is sufficient similarity to suggest that Townsend's definition (iii), like Jazairi's, could act as a basis for formulating disability indicators and indices measuring degree of disability.

Conceptual Schemes

It should be noted that Townsend's five meanings are not explicity linked, with one another. By contrast, Jazairi's definition introduces a concept of causality towards which scientific medicine seems likely to be sympathetic, ie the limitations of activity are 'due to illness: illness 'results in' limitations of activity. Jazairi puts two concepts, illness and activity limitation, into relationship with one another. Also, he gives the context within which each of the two concepts is used some description in terms of the other one: he has produced what might be described as a conceptual scheme.

There seems little doubt that conceptual schemes for disability experience are a great help to clarity of thinking and can have considerable explanatory power, especially when the context in which they are to be used is made explicit. Thus Slater and his colleagues (1974) drew attention to the value of 'conceptual schemes' in which disability is regarded as the consequence, not merely of illness, but of disease and impairment. They considered that 'the terminological differences which have plagued disability studies appear more recently to have lessened, as increasingly disability is viewed in terms of functional limitations and behavioural consequences of impairment and disease processes'. (underlining added).

Nagi's scheme

The author of much of the seminal work in which disability experience is viewed in terms of a conceptual scheme is Saad Nagi (1965, 1969) whose call for a rationalisation of terminology was cited in Chapter One. He began by differentiating:

i. active pathology or disease process: a state of mobilization of the body's defences and coping mechanisms.

ii. impairments: anatomical and/or physiological abnormalities which result from disease but are often residual after the active stages of pathology have been arrested or eliminated.

iii. functional limitations: resulting from impairments and representing an individual's loss of ability to perform the tasks and obligations of his usual roles and normal daily activities.

iv. sickness and illness: forms of behaviour that evolve when the presence of disease in pathology is perceived.

v. disability: forms of behaviour that evolve in situations of long-term or continued impairments that are associated with functional limitations. (Nagi, 1965 pp 101-104).

Nagi then extended his discussion of disability, illness and sickness by suggesting that the pattern of behaviour arising from disability is

shaped by the same influences as those which shape sickness and illness. These influences are of three kinds:

i. those characteristic of the pathological condition itself.

ii. those which arise from the definition of the situation by the afflicted.

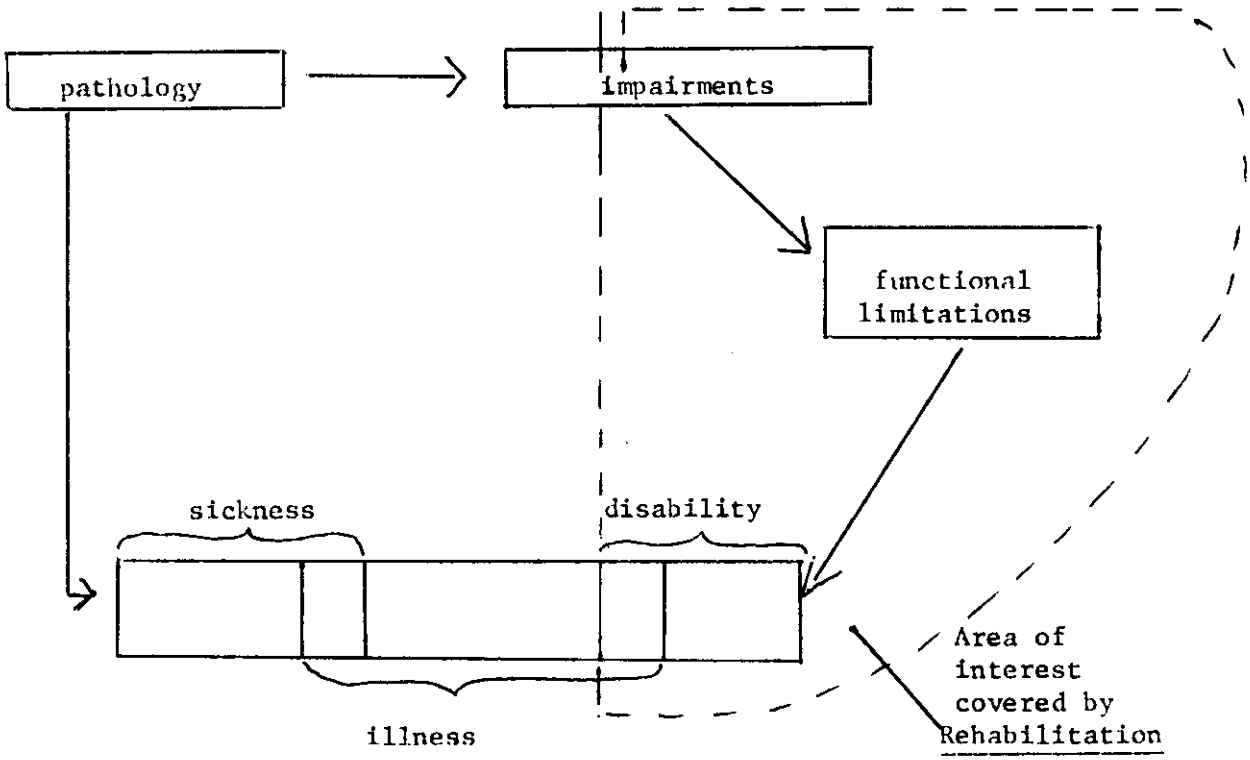
iii. those which arise from the definition of the situation by others, particularly 'significant' others, such as members of patients' families, their friends and members of the health professions caring for them (ibid).

Nagi also pointed out that, while the pattern of behaviour arising from disability is shaped by the same influences as those which shape sickness and illness, disability must be carefully distinguished from these states, especially that of illness. Disability, unlike illness, may be present in the absence of disease. Injury and genetic factors, for instance, often give rise to permanent impairments which ensue in functional limitations and disability. Nagi also makes a firm distinction between 'sickness' as a term which can be used to summarise the behaviour ensuing from acute conditions of short duration, and 'illness' as a term summarizing the behaviour ensuing from chronic conditions.

Even a superficial examination of these various concepts in Nagi's writings show that he has defined them so that they have unambiguous relationships with

one another. These relationships can be expressed with little loss of meaning by means of a conceptual scheme of the kind shown in Figure 2.1 below. The arrows in the scheme have the meaning ''result(s) in''.

Figure 2.1 Nagi's disease and disability concepts expressed in a conceptual scheme



Schemes as 'models'

Several points should, be emphasized about Nagi's conceptual scheme. The first, and this applies to any scheme of this kind, is that it supplies a picture or pattern of disability - how disability 'works'. Hence it has features in common with the 'models' which scientists often use to describe the relationships that familiar events and concepts have to one another and to the ultimate structures of the natural world. One feature of such models to which philosophers of science often draw attention is that not all aspects of the theories modelled are necessarily reflected in the models themselves (Braithwaite, 1959). In the conceptual

scheme shown in Figure 2.1 the psychological and social forces which shape the actual behavioural manifestations of pathology and impairment are not specified. The converse is also true; models often suggest features of the theory they express which are not really there. Perhaps a more careful drawing of Figure 2.1 would have obliterated any impression that disability as defined by Nagi can result directly from pathology or disease processes without an intermediate expression in impairment.

Although, as is suggested above, Nagi's conceptual scheme has features in common with a 'model' of the common experience of disease consequences, he does not present it as such. However, Williams et al. (1976) and Williams (1979) have developed a model of disability which is indeed a 'model' in the proper sense of that term. In the first of these papers 'an intuitive construct or concept of disability' in the sense of inability to perform activities of daily living was presented; it was also suggested that individual activities, when treated as items in a scale, will behave as if they were members of a cumulative scale, i.e they keep the same order of difficulty for most members of any group of disabled people to which they are deemed to apply. The second paper was aimed both at developing this model of how disability items behave and at comparing the model with other possible models which also might be used to explain this behaviour.

Williams describes three models or theories of disability. The first is the 'mechanistic' theory. However, rejecting 'crude' mechanism (which assumes that, just as disability is caused by impairment, so the pattern of

disability is caused by the pattern of impairment), he elaborates a second model - one of 'refined' mechanism. This is Nagi's model; it is also the usual medical model of disease consequences. Williams describes it thus:

> 'To explain the pattern of disability suffered, one must look not only at the type of impairment but also at the customary activities of the person impaired. But since the impairment remains basic, its presence in a limb or body system creates disability in the person who uses that limb or body system for an important activity. Consequently, if a disability appears at all, it is referable to the locus of impairment.'

William's criticises this model severely. After pointing out that it works better for impairments with a clear locus - for an amputated limb better than for a circulatory or respiratory problem, he virtually gives it the coup de grace by means of a quotation from a paper by Nichols (1975) in which, after close reasoning, he ended: 'we are thus left with the uncomfortable conclusion that traditional clinical measures of outcome are unrelated to functional capacity.'

The alternative theories put forward are the 'rational choice' theory, for which breathlessness is the classic case, and the 'deviance' theory (Freidson 1972), of which the 'stigma' theory of Goffman (1963) is a variant. These latter theories emphasise the restrictions placed on a disabled person by the necessities of the classification given him by others. Both 'rational choice', by which is meant that a person can to some extent choose his disabilities, and 'deviance' will obviously upset the orthodox Guttman order of activity restrictions in individual cases.

Culyer has added a 'comment' to Williams's paper in which he elaborates a more general 'choice' theory of disability (dropping the 'rational'), which subsumes the mechanistic and deviance theories:

> 'My own hunch would be that the rational choice hypothesis ... best applies to the young disabled, among thom one would expect to see a high variance of disability given basic impairments - depending on tastes, determination, parental wealth, social expectations, etc, The ''conservative irrational'' model might be a useful starting point in modelling the disability of elderly persons.'

Culyer ends his comment with practical suggestions about the use of the 'choice' model as a basis for framing social policies designed to help the disabled.

Uses of Nagi's conceptual scheme

In the previous section it was suggested that Nagi's scheme of terminology can serve as a 'mechanistic' model of disease consequences. As a model of this kind it illuminates certain issues within rehabilitation medicine. For instance, it can be employed for defining the boundaries of rehabilitation and for distinguishing rehabilitation from other branches of health care. Rehabilitation aims to restore optimal functioning and to integrate the disabled person in society. Hence, in terms of the conceptual scheme in Figure 2.1 (p.19). rehabilitation is concerned with the area inside the dotted line, ie with functional limitations themselves and with disability, but not with sickness and much of illness.

Another point clarified by Nagi's terminology is the overlap in the types of treatment given by rehabilitation professionals and other professionals. Figure 2.1 shows this overlap as relating to an overlap between illness and disability; ie the overlapping treatment refers to those behavioural manifestations which chronic illness and disability have in common.

Compensation for disability

In the second presentation of his definitions, Nagi (1969) does not rework these to any great extent. The main change is that he gives less place to the mediating role of functional limitations. These appear to be assimilated either to impairment or to disability, so that disability is conceived as ensuing directly from impairment. The definitions of these terms now becomes:

> 'impairment indicates a physiological or anatomical loss or other abnormality, or both.' (Ibid, p.11)

> 'disability refers to a pattern of behaviour that evolves when impairments impose limitations upon the individual's capacity and levels of functioning.' (Ibid, p.12)

A possible reason for this change could be extremely important. In the 1969 book disability and related terms were discussed primarily in the context of the assessment of disability for compensation and benefits. In this context there may be less need to distinguish a mediating term between impairment and disability such as is provided by a concept of functional limitation.

In fact, the emphasis in establishing compensation is almost wholly on impairment, particularly those impairments which arise from injury occurring while work is actually being done. These are compensated whether or not they actually result in loss of earnings. (The same is broadly true of British schemes such as the Industrial Injuries measures.) However, though compensation is based firmly on impairments, the American legislation refers to impairment as 'permanent partial disability'. As a result, considerable conceptual confusion of the kind referred to in Chapter One has arisen.

This particular issue - the tension between medical and administrative definitions of 'disability' within legislation governing the provision of benefits - is illuminated further by Kessler (1970), who has made a close study of the matter in an American context. He shows why there is always the possibility of conflict between medical and administrative viewpoints. Extracts from Kessler's book, showing how, in theory at least, any conflict might be resolved by a clear definition of the duties and responsibilities of each profession, are quoted at the end of Chapter Eleven (p.155).

Nagi (1969, p.13) also makes the general point that clear definition of areas of responsibility helps to reduce the possibility of conflict between doctors and administrators. Another good example is the way in which the American Medical Association Committee on Medical Rating of Mental and Physical Impairment (1971) has made a clear distinction between impairment and disability in its proposals for evaluating permanent impairment, pointing out that medical practitioners are concerned only to assess impairment.

Disability and Interaction

Other insights can be drawn from Nagi's writings. First, he cites several examples of medical conditions such as severe hypertension, pulmonary emphysema and severe arthritis in which both illness and disability can be consequences of pathology at the same time (Nagi, 1969). Common headaches and controlled diabetic conditions are given as examples of illness without disability - there is no limitation in the performance of normal roles. Healed amputations and residual polio paralysis are given as examples of disability without illness.

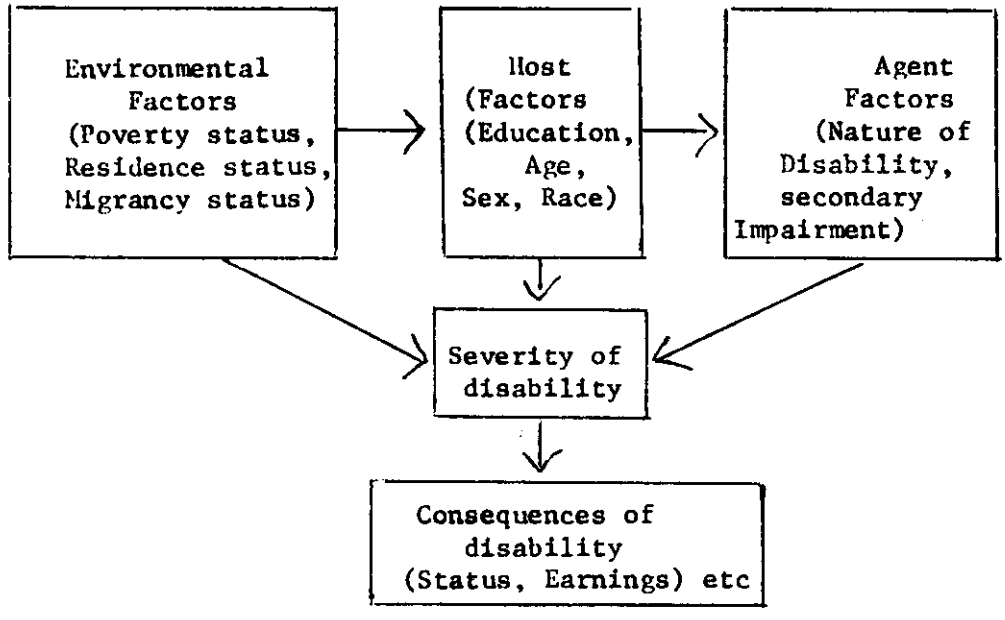
Secondly, in defining disability as a behavioural consequence of impairment, Nagi (1965) emphasised that personal and social factors interact with health factors in determining the actual pattern of behaviour manifested. He therefore opened up the possibility of making a connection between the 'scientific-medical' (or professional-medical) definitions of disability and its related concepts and those definitions in which disability is viewed as a social process or as a system of social control. Haber and Smith (1971) point out that even a working definition of disability set in an American Social Security context should take some account of environmental social and psychological processes. There seems no reason why a conceptual scheme in its role of model should not make explicit reference to processes of this kind, although introducing them into Figure 2.1 would overload the diagram and could result in a misinterpretation of the 'model' of disease consequences implied.

Some recent conceptual schemes of disease consequences

In the last decade several researchers have devised conceptual schemes of disease consequences which emphasise environmental and social processes and their interaction with health states. Two examples are those of Wan (1974), and Warren (1977).

Wan's scheme is described by its author as an 'epidemiological model' of disability. A major place is given in the model (shown in modified form in Figure 2.2) to what Wan calls 'environmental' and 'host' factors. He regards these, together with 'agent factors', such as the abnormal condition itself, as 'pre-conditions' of disability. The result is a model which aims to suggest the complexity of the inter-relationships among the three 'epidemiological' factors and their consequences.

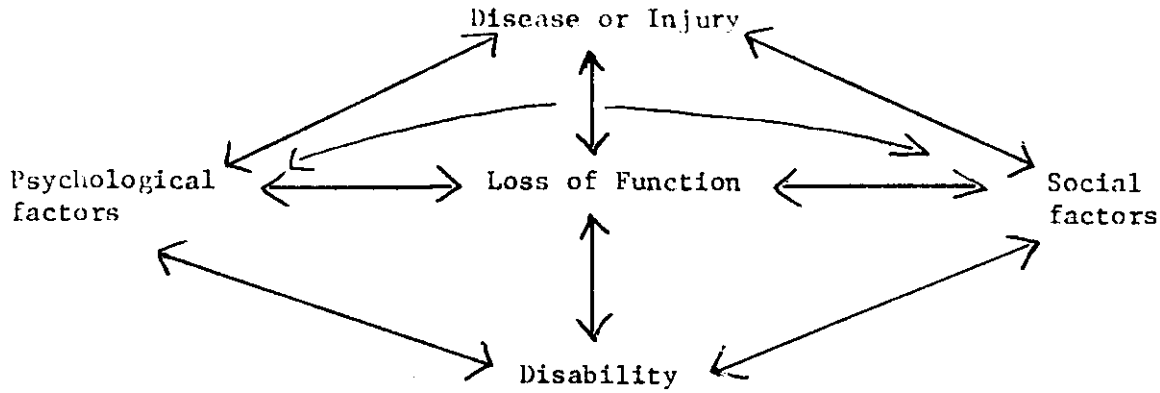
Figure 2.2 An epidemiological ''model'' of disablement, (Wan 1974)



Warren's scheme is essentially a 'rehabilitation' model of disease consequences. He has described it as showing 'factors inter-relating levels of disability'. The main feature of this model, shown in Figure 2.3, is its use of double-headed arrows to indicate interaction rather than consequence or causality, ie the model shows how psychological and social factors interact with disease processes to determine the actual form which loss of function takes. These factors also interact with loss of function to determine the course of disability, and with disability itself, presumably to determine its consequences.

Warren's main aim in presenting this model of the rehabilitative process was to emphasise the critical role of social, psychological and environmental factors in determining the nature and severity of the disability shown by people undergoing rehabilitation. It seems that, in the past, it has been a common tendency in medical practice to pay insufficient attention to these factors. According to Warren, in terms of Figure 2.3 '... too often effort is concentrated on the central vertical pathways - the upper pathway being the concern of the appropriate consultant or general practitioner and the lower one the concern of consultants in physical medicine ...' (op. cit., p.1279). Hence, without the inclusion of psychological and social factors in the model, rehabilitation could appear to be the concern of medical practitioners alone. With the inclusion of these factors, both the importance of the influence of social and psychological factors on the actual behaviour manifested by patients and the roles of other health professionals within rehabilitation are emphasised.

Figure 2.3 Factors inter-relating levels of disability (Warren 1977)



Definitions and social forces

Wan's and Warren's models illustrate the modern tendency within medicine and health to formulate definitions of disability and related concepts which take account of social processes. More importantly, these processes or 'forces' are viewed as acting together with disease to produce the overt manifestations of disease consequences. Thus, using Nagi's definitions but modifying his conceptual scheme, 'disability' is indeed the consequence of impairment, but of impairment interacting with social forces and not of impairment by itself.

The tendency to form definitions of disability which recognise the importance of social forces can also be illustrated by the last two meanings of 'disability' cited by Townsend (1967) and noted at the beginning of this chapter. As Townsend implied, when a term acquires several distinct meanings, it has really lost the power to contain all the possible disparate meanings of the concept it defines. Separate terms are needed and their relationship to one another needs specifying. As has been shown in this chapter, a substantial part of this work was undertaken by Nagi in his separation of the terms 'impairment', functional limitations' and 'disability'.

This process of precise definition and specification has been taken further by Dr P H N Wood in devising proposals for the classification of disease consequences for the World Health Organization (Wood, 1975). He has used the term 'handicap' to specify the more overtly social consequences of disease processes. By incorporating this term into a scheme of inter-related concepts most of the five meanings of disability specified by Townsend (supra p.15) are individually delineated by one term or another. In addition, in Wood's scheme, the logical and practical relationships of the terms to one another are clearly described so that they can be used to form the basis of a sound classification of disease consequences. A discussion of the use of the term 'handicap' in modern 'disability' writings, particularly within Wood's work and the recent WHO proposals based on it, is the main subject of the next two chapters of this study.

CHAPTER THREE

THE CONCEPT OF 'HANDICAP'

Popularity of the term 'handicap'

Of all the terms used to express the consequences of disease, 'handicap' is the one which bears the greatest variability of meaning, probably because it is so often used without prior definition. One common usage, to which Lees and Shaw (1974, pp. 4-5) have drawn attention, is merely as a vague synonym for disability and impairment. Nevertheless, as Agerholm (1975b) has pointed out, 'handicap' is sometimes used in official writing and even legislation in this vague way. Blaxter (1976) suggests two explanations for the imprecision of much legal terminology when dealing with medical matters. Her first explanation is that legal definitions tend to be based on the inevitably loose definitions of the community; her second is that they are usually only required in such a narrow context that legislators have felt able to assume that misunderstanding is unlikely to occur among those who require access to legislation. Hence legislators often use simplistic descriptions (deafness, blindness, etc) for the diseases or impairments mentioned. 'Handicap' is used as a similarly simplistic collective term for disorders, diseases, injuries, together with their effects.

A 'Handicap' Terminology

This accepted usage of the term 'handicap' probably goes some way to explain why Agerholm's classification (1975a), which is itself based on the use of the term 'handicap' in a startlingly simple way, has met with a

ready response among many workers for the 'handicapped', both professional and voluntary. She defined handicap and its two sub-divisions, 'intrinsic' and 'extrinsic' handicap as follows:

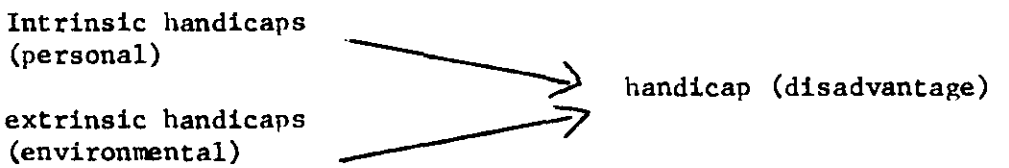
> A handicap is a long-term disadvantage which adversely affects an individual's capacity to achieve the personal and economic independence which is normal for his peers.
>
> An intrinsic handicap is such a disadvantage arising from the individual's own characteristics from which he cannot be separated.
>
> An extrinsic handicap is such a disadvantage arising from the individual's environment or circumstances (ibid).

Basic to these definitions is that handicap is primarily to be equated with the experience of disadvantage, and that this disadvantage arises either from an individual's 'characteristics' or from his other circumstances. Thus far, in fact, these definitions seem unexceptionable, there is a careful delineation of the concept in question and there is the nucleus of a causal mechanism for its existence. However, the examples of 'handicap' which Agerholm gives suggest that there might be a mismatch between her definition and the thing defined:

> '... people's handicaps, their blindness, their funny gaits, deafness, ...'

It seems clear that in this terminology, in which 'handicap' is conceived as disadvantage, 'handicaps' are not regarded as disadvantages, but as the

entities, intrinsic or extrinsic, which give rise to handicap. In terms of the causal notation used in the previous chapter the 'model' which is being described seems to be:



If this is fair comment on Agerholm's ideas there appears to be no conception of handicap being the consequence of an interaction between intrinsic (biological) and extrinsic (environmental and social) factors. However, whatever the faults of her terminology and basic model, Agerholm's classification of 'intrinsic handicaps' has considerable value and will merit further discussion in Chapter Seven of this study.

Mitchell's terminology

Mitchell (1973), whose editorial calling for a clear terminology was discussed in Chapter One, is another writer whose attempt at devising a clear usage for a popular term like handicap was not entirely successful. Like Agerholm, in his definition of disability and his implied definition of handicap, he loses the idea of a causal sequence in the terms. As a result, the distinctions between the concepts he uses to describe disease consequences are not entirely clear. Thus 'disability' appears to be part of a concept of abnormality or impairment:

> 'The word disability refers to abnormality which interferes with function to a significant degree. A complete diagnosis should describe the disability, the abnormality underlying it and the cause of the abnormality' (Ibid).

At the same time, handicaps appear to be a sub-set of disabilities. This comes out particularly clearly in a reference (see below) to certain impairments and disabilities as 'constituting' handicaps. However, he has given excellent descriptions of particular experiences of handicap and of the circumstances in which handicap conceived as the consequence of impairment and disability might arise:

> 'A child may be born with one finger-nail missing. This is a malformation but does not constitute a disability, since it does not interfere in any material way with the function of the hand. A man with red-green colour blindness has a disability since he cannot distinguish colours: whether it constitutes a handicap or not depends on his circumstances. If he is a farm labourer it is unlikely to be a handicap an indeed he may be quite unaware of it.
>
> If, on the other hand, he starts work as an engine driver, the colour blindness may be such a handicap that he cannot pursue his occupation. In the same way a degree of intellectual sub-normality which is only a slight handicap to a child in a remote rural community may be much more serious in the child of university graduates living in a large city, of whom more is expected. Moreover, whether the child can be kept in a particular class or school may depend not only on his own disability but also on the tolerance of the teacher, the number of other pupils, and so on. Thus the extent to which his disability affects his education, and therefore his life, depends on factors other than the disability itself.' (Ibid)

Mitchell clearly regards it as desirable to describe handicap in terms of an interaction between environmental circumstances and of impairment or disability itself.

The OPCS survey terminology

Yet another use of the term handicap which has had considerable influence in this country is that promoted by the report of the survey of households conducted by Amelia Harris and her colleagues for the Office of Population Censuses and Surveys (OPCS) in the late 1960s. The study (Harris et al, 1971) aimed to give, inter alia, an estimate of the numbers of 'impaired' and 'handicapped' people aged 16 and over living in private households in Great Britain. To obtain reliable estimates, precise definition or, more exactly, precise operationalization of working definitions, is obviously crucial.

The definitions of the key terms used in the OPCS study are reported as being based on earlier definitions suggested by Jefferys and her colleagues (1969):

> Impairment is 'lacking part or all of a limb, or having a defective limb, organ or mechanism of the body'.
>
> Handicap is 'the disadvantage or restriction of activity caused by disability'. (Harris et al, op. cit. p.2).

For the purposes of the OPCS study, however, the definition of impairment was modified as follows:

> 'Impairment is
>
> i. lacking part or all of a limb or having a defective limb; or
>
> ii. having a defective organ or mechanism of the body which stops or limits getting about, walking or self-care.' (Ibid).

The effect of the change in the definition of impairment is that those people with impairments which do not limit mobility, work or self-care are not counted as impaired in the survey unless they also have an impairment of a more obviously physical kind. Operationally, this seems sensible, since if conditions such as a moderate degree of short-sightedness, controlled diabetes or the loss of teeth were counted as impairments, nearly everyone would be impaired. However, the mere loss of a finger always counted as an impairment in the survey even if it presented no problem of mobility, self-care or employment. In consequence, especially when one takes into account the operationalization of the definitions in terms of the questions asked in the course of the survey, there is a clear emphasis on 'physical' as opposed to sensory or mental impairment.

The same kind of problem arises with the OPCS definition of 'handicap'. As a working definition this seems rather confusing; adding a rather vague concept such as 'disadvantage' to a much more exact concept of restriction of activity is bound to be so. However, the operationalisation of the definition has resulted in a concentration on handicap entirely in the latter sense. As a result, people suffering from quite severe mental or sensory impairments were not included among the handicapped unless they were also physically restricted.

Hence Harris reports that

> 'a man who is totally blind or deaf or mentally impaired would not be included [among the handicapped] unless he feels his impairments limits in some way his getting about, walking or taking care of himself, or he also has some physical impairment. The same conditions apply to disorders such as diabetes or epilepsy'. (Ibid, p. 4).

One other interesting point arises from this quotation - the use of the word 'feel': a seriously impaired man would not be counted as 'handicapped' unless he feels that his impairments limit his activities. The use of this word reminds us that in a survey or census as extensive as the OPCS survey of 1968-9, self-report procedures must of necessity be used. In these circumstances the validity of the data produced by an operational definition which appears to be precise can be less than that hoped for. Harris and her colleagues recognise that this can happen and introduced other careful reservations into their findings, for example

> 'There are in some cases, reasons for some impairments not being admitted, lest they become (ever greater) handicaps. A man who holds a driving licence, and whose sight has deteriorated, may be reluctant to admit to this in case he loses his licence, or an epileptic, fearing that his condition might lead an employer to dispense with his services, may not be prepared to admit to his condition.' (Ibid)

Nevertheless, whatever its limitations, the OPCS terminology has been found useful as a basis for clear writing. The DHSS Report on benefits in European countries cited in the first Chapter (DHSS, 1972) was able to make use of it by equating 'handicap' with the British Social Security usage of 'incapacity': 'The handicapped person is a person who is incapable of doing what the normal person can do, whether in terms of earning capacity or of working capacity' (op. cit., p. 6).

American usage

The terminological schemes implicit in the writings of Agerholm, Mitchell and Harris represent a considerable, though incomplete, clarification of the terms, particularly 'handicap', which are commonly used to refer to disease consequences. As such these schemes represent a broad movement towards precision in British writing. In the United States, however, few

of the medical writers who use a reasonably clear terminology so much as mention'handicap'. This is especially true of those who write from within rehabilitation medicine. It would however be totally unfair to suggest that the focus of rehabilitation in the United States is so much on the restoration of physical function that the social and psychological consequences of impairment are considered to be of little consequence. Solokov and his colleagues (1959) were quite clear on the point: '... disability, as opposed to impairment must be gauged on the basis of social, psychological and vocational factors, as well as medical factors'. Similarly, in the authoritative 'Handbook of Physical Medicine and Rehabilitation' Stolov (1971), after defining disability as 'lost function', emphasised that the 'functions' lost could include employment and that disability should be described in terms of 'loss of social, vocational, avocational and psychological function' as well as of physical function.

However, while medical writers do not much use the term, 'handicap' is widely used by American medical sociologists to summarise the area of experience covered by the last two of the five meanings of 'disability' stated by Townsend (1967) to which attention was drawn on at the beginning of the previous Chapter:

> 'iv. a pattern of behaviour of a socially deviant kind
> v. a socially defined position or status, usually of inferiority.'

Townsend was, in fact, referring to the theories of social behaviour in which disability has been analysed as deviance (Mechanic, 1968) or as stigma (Goffman, 1963).

In his paper, Townsend also listed several other writers who use 'handicap' with these or similar connotations. Two of them, Freidson (1966) and Myers (1966), have so used handicap in the context of rehabilitative medicine. Freidson regarded handicap as 'disability manifesting itself by means of social and cultural variables as opposed to biological and psychological variables'. He conceived it primarily in terms of deviance from norms: 'handicap is an imputation of an undesirable difference from others: a person said to be handicapped is so defined because he deviates from what he himself or others believe to be normal or appropriate'. For rehabilitation the implications of conceiving handicap in this way are profound. Rehabilitation becomes much more the correction of deviance from social or individual norms, much less the correction of malfunction alone. The balance, Freidson suggested, is provided by the American National Council of Rehabilitation's definition of the task of rehabilitation as that of restoring 'handicapped' persons to 'the fullest physical, mental, social vocational and economic usefulness of which they are capable'.

Myers's work is valuable because he has traced the change within rehabilitation medicine in terms of the changes in the definition of its task as suggested by various writers during the previous two decades. 'In the field of rehabilitation' he wrote, 'disability was defined narrowly to include only the physically handicapped. Over time, the term has been broadened to include mental and emotional impairment, chronic illness and ageing as well'. This broadening of the scope of the concept of disability has, he suggested, been paralleled by a broadening of the concept of rehabilitation itself - 'at first it was centred in pathology, then it broadened to include vocational as well as medical efforts'. As a result of this broadening, rehabilitation is obviously venturing into areas in which social concepts are important,

i.e. as Myers put it, rehabilitation is now viewed as the 're-establishment in society of the patient within the limits of his handicap'. Among medical sociologists in the United States, therefore, 'handicap' is a term used to describe the explicit social consequences of disease processes.

'Handicap' in work for the WHO

In recent years there have been a vigorous international attempt to clarify all the main concepts used to describe the consequences of disease, particularly within rehabilitation. Much of this work of clarification has been undertaken for the WHO by Dr P H N Wood of the Arthritis and Rheumatism Council's Epidemiology Research Unit located at Manchester University, England. Wood's brief was to prepare a classification of 'the consequences of disease' on the lines of the International Classification of Diseases (ICD). His first presentation (Wood, 1975) was a draft 'Classification of Impairments and Handicaps' prepared for an international conference for the ninth revision of the ICD in 1975. He has since continued his work and has prepared several papers with colleagues which clarify the ideas developed. Recently, the final version of the classification has been published for trial purposes in response to a resolution (1976) of the World Health Assembly. This Classification will be discussed in detail in Chapter Six.

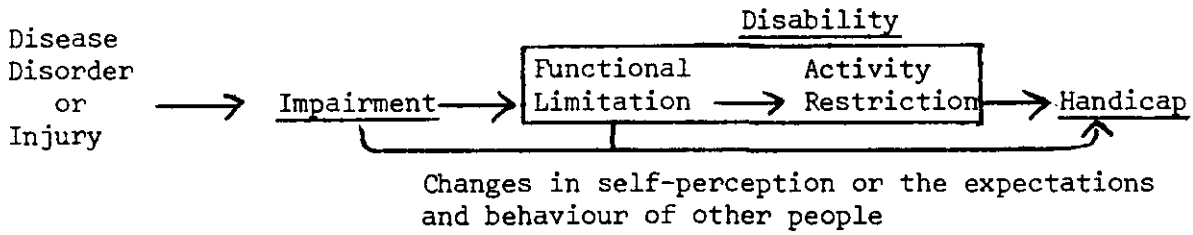
Wood's first concern was to develop a clear and consistent terminology. Hence he began his draft paper by discussing the value of making clear distinctions between the terms commonly used to express aspects of disease consequences. He then defined the three terms, 'impairment', 'disability' and 'handicap' and linked them together in a conceptual scheme in such a

way that handicap is seen as consequent on disability, disability on impairment, and impairment on disease etc., i.e. using the notation developed in the previous chapter:

disease impairment disability handicap

These terms maintain their key role in the various papers developing the scheme and indeed in the final version of the classification (WHO, 1980). A useful elaboration of Wood's interim scheme has been suggested by Taylor (1977). This, as well as Wood's own presentation, is drawn on for Figure 3.1.

Figure 3.1 Wood's terminological scheme



Taylor's elaboration on Wood's basic scheme in Figure 3.1 seems to depend on a theory of how the state of handicap ensues from those of impairment and disability (changes in self-perception etc). It is implied that handicap primarily reflects an individual's inability to play a personally acceptable social role and that the degree to which an individual is perceived as impaired by others will also have an effect on the degree of handicap which ensues.

Some Problems of Terminology

In some of the papers in which Wood and his colleagues explain the development of their thinking since the interim proposals were published in 1975, another term - 'disablement' - has been suggested for use in exact writing to cover the whole unitary concept in which impairment, disability

and handicap are separate entities (Wood and Badley, 1978). Wood (1980b) has since repeated this idea in a glossary of terms originally prepared as an appendix to the International Classification of Impairments, Disabilities and Handicaps (ICIDH, WHO, 1980). One disadvantage of using disablement in this way, however, is that yet another term which requires translation would be being introduced into a WHO scheme. The problems of definition are severe enough without this further burden. A similar observation was, in fact, made by those British observers who, studied the social security systems of several European countries. Their report states:

> 'Terminology causes particular problems in international studies, because to the inherent uncertainty about terms there is added the uncertainty about how to translate them. This applies to the provisions of the various (social security) schemes and equally to the bodies administering them. Two English language publications issued by the one country may contain quite different terminology; and successive hosts will use quite different words to describe the same thing. Again, (this) report attempts to achieve consistency - sometimes at the price of using a rather awkward term in place of what is not really a translation but an attempt to find a roughly equivalent term in the United Kingdom schemes.' (DHSS, 1972, pages 6 and 7).

Another disadvantage of using the single term 'disablement' to cover disease consequences as a whole is that the term is already used in a systematic way within the British War Pensions and Industrial Injuries Pensions schemes, especially the latter, to mean 'the overall effect of the relevant disabilities' (DHSS, 1970). The context in which this meaning is to be understood is compensation for 'loss of faculty' i.e. impairment. To quote the British observers again:

> 'A scheme ... would be concerned with disablement if it provided compensation for loss of faculty irrespective of the social and economic implications of that loss'. (op cit., p. 6).

If we add the problems of translation to those of definition, any scheme which introduces a fourth term could well prove unacceptable to the WHO's varied interest groups.

If the terminological scheme depicted in Figure 3.1 is compared with that of Nagi (Figure 2.1, p.19), the only really important difference is that an extra term, 'handicap', has been grafted on to the end of Nagi's main disability sequence. However, the precise content of the important terms, impairment, disability, handicap, etc. in any conceptual scheme is mainly a means to an end: to enable experience to be organised and structured, eg in term of a classification, without confusion. Nevertheless, a good deal of the first Section of the ICIDH is taken up with an exposition of recommended definitions of the terms impairment, disability and handicap and their practical advantages. Hence the next Chapter of the present study will begin by pursuing this particular theme.

CHAPTER FOUR

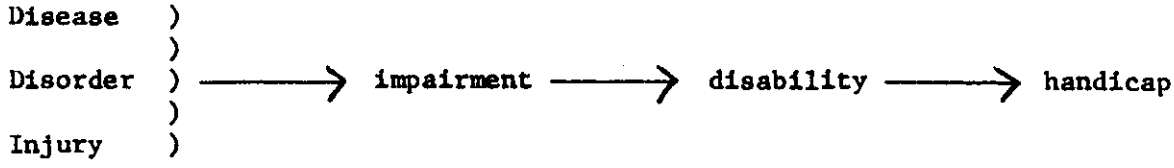
THE WHO SCHEME OF TERMINOLOGY

Development of the ICIDH

The proposed International Classification of Impairments, Disabilities and Handicaps, (ICIDH; WHO, 1980) is subtitled 'A Manual of Classification relating to the Consequences of Disease. The Introduction to this work outlines the various stages in the evolution of the proposals and begins by showing how the first steps in devising the classification took the form of an attempt to reconcile proposals emanating from the WHO Centre for the Classification of Diseases in Paris with the pragmatic approach to classification characteristic of the ICD.

Central to this work was the devising of the conceptual framework described briefly in the previous Chapter and in detail in Wood's draft proposals of 1975. Since 1975 agreement has been secured on the usage of the most important terms in this framework between a number of international agencies. In consequence, the basic conceptual scheme of the ICIDH, shown in Figure 4.1, does not differ in essence from that of the draft proposals (Figure 3.1 p 40).

Figure 4.1 Simple scheme of ICIDH concepts



This scheme of concepts is presented in the ICIDH as a means of providing a model of the process of health experience from the onset of pathological

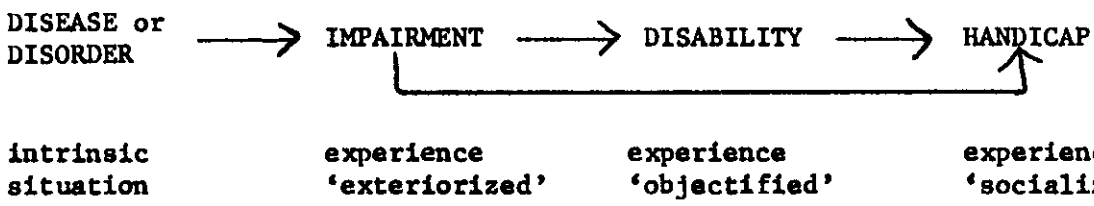
changes to their final issue in 'handicap'. In Section One of the Classification, entitled 'The Consequences of Disease', it is pointed out that at the present time and in contrast to times now past, chronic illness and medical responses to it occupy a dominant position in health experience, especially in developed countries. Hence of necessity a good deal of attention needs to be focussed on the disabling and handicapping consequences of disease, since these reflect the chronic nature of much suffering. It is suggested that those who suffer chronic illness, the health professionals concerned to help them, and the policy-makers and planners who seek to adapt services to needs, alike encounter practical difficulties in this shift of emphasis from pathology to its consequences. It is also suggested that these difficulties stem partly from the lack of a coherent scheme or conceptual framework, such as is provided by Figure 4.1, by means of which the nature of disease consequences and their attendant suffering can be explored.

Analysis of sequence of concepts

The conceptual scheme in Figure 4.1 is therefore presented to meet this lack, the experience of chronic illness being analysed in terms of the sequence: impairment $\longrightarrow$ disability $\longrightarrow$ handicap.

The sequence is, however, more clearly expressed in the WHO proposals by putting it into a form which shows both more detail and the perspective within which each concept in the sequence is used: impairment 'exteriorizes' or 'reveals the facts' about the situation of disease experienced in a particular case; disability 'objectifies' it, and handicap 'socializes' it. This more detailed model is shown in Figure 4.2 and is taken from p.30 of the ICIDH. The notions of 'exteriorization', 'objectification' and 'socialization' which provide useful summary descriptions of the significance of the successive planes of experience of disease consequences, are discussed fully in the text of the ICIDH. (Ibid, p.27).

Figure 4.2 ICIDH 'model' of disease consequences



However, it is still important to study carefully the full formal definitions and 'characterization' of the terms impairment, disability and handicap because compared with the draft proposals, there are significant changes to the definitions of impairment and disability. The concept of 'functional limitation', which was previously considered as a 'plane' of disability, has now been assimilated to impairment so that term impairment is now used to relate to defects of both structure and function.

The formal definitions read as follows:

i. Impairment In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

ii. Disability In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

iii. Handicap In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. (Ibid, p.27).

Because an understanding of the precise terms in which these definitions are stated is vital to an understanding of the WHO classification as a whole, the definitions are shown again, alongside the characterizations which accompany their formal statement, in an Appendix to the whole study.

Examples of the sequence

As in the conceptual scheme basic to Wood's draft proposals, shown in Figure 3.1, p. 40 , the representation of experience consequent on disease or disorders show in Figure 4.2 is intended to suggest that handicap might well result from impairment without the mediation of disability. The examples of this situation given in the ICIDH relate to the experience of disfigurement generally and to that of a child with coeliac disease. Neither experience, it is suggested, usually includes activity restriction (disability) but disadvantage (handicap) may result from embarrassment in the first case and from inability to partake of the same food as other children in the second.

By means of further examples attention is also drawn in the ICIDH to other implications of the sequential nature of the concepts in Figure 4.2 and to the carefully drawn distinctions between them in the definitions and characterizations. There is always, as both Mitchell (1973) and Harris et al., (1971) perceived, the possibility of interruption in the sequence implied by the model. Thus Mitchell's example (supra p.29) of a man with colour blindness is elaborated - in this case impairment is only likely to result in handicap if the man aspires to being an engine driver or to some other kind of work for which red/green colour blindness would disqualify him. Similarly, Harris et al's much quoted example (1971, p.2) of a woman who has had a finger amputated is only likely to be handicapped in any significant way if she is a typist or a pianist.

Attention is drawn to other important implications of the ICIDH terminology. Thus one feature of impairment which Wood remarked on in his draft proposals is its ubiquity:, probably everyone is impaired to some degree and in some way, often through slight defects of sight or hearing. Hence, in discussion the definition of impairment it is implied in the text of the ICIDH that when classification proceeds trivial impairment is to be ignored:

> 'Impairment represents deviation from some norm in the individual's biomedical status, and definition of its constituents is undertaken primarily by those qualified to judge physical and mental functioning according to generally accepted standards'. (Op. cit., p.27).

Another implication of the sequential nature of the concepts is recalled by the simple example of the woman with an amputated finger above: there is no necessity of high positive correlation between degrees of impairment, disability and handicap. It follows that it is seldom possible to make categorical statements about the handicap experienced in particular cases merely from observations or measurements of impairment or disability. Reference must always be made to the experience of the individual in his normal life in the community. Another good general example of the lack of correlation between disability and handicap is given in the Chapter in the ICIDH entitled 'The Consequences of Disease':

> 'One individual with rheumatoid arthritis may be only mildly disabled and yet at a severe disadvantage, whereas another person with the same disease who is much more severely disabled may, perhaps because of greater support from the family or social network, experiences considerably less disadvantage'. (ibid, p.30).

Applications to mental impairment

Several of the examples given in the ICIDH of the application of the concepts in the sequence apply just as much to 'mental' and 'sensory' as to 'physical' disease consequences. Mental impairment provides what is described as 'perhaps the most graphic example of someone who is handicapped without being disabled'. The example is of a person who, having recovered from an acute psychotic episode, bears the stigma (handicap) of being a 'mental patient' even though neither the impairment nor a consequent disability actually exist. It is also pointed out that the consequences of mental disease include what might well be in Britain the most intractable problem in a widespread application of the ICIDH terminology -

the almost universal use in Britain of the term 'mental handicap' to describe the consequences of disorders which result in an IQ deficit (standardized IQ $<$ 50) which the ICIDH would classify as a moderate or severe psychological impairment. The use of the term 'mental handicap' it is suggested, can be seen as 'a trend to euphemism with the loss of important distinctions'. However, in addition to this broad criticism, the commonly accepted use of the term 'mental handicap' is seen as representing hopelessly inexact usage:

> 'the disadvantage experienced by individuals with psychological impairments can vary, so that it is inappropriate to refer to a handicap as 'mental'. Thus the descriptive adjectives 'mental' and 'physical' may correctly be applied to impairments, but their use in relation to disabilities is loose and to handicaps quite unsuitable. It is perhaps vain to hope that the tide of careless usage can be reversed, but at least in serious discourse the logic of terminology should be exploited to reinforce the conceptual framework'. (Ibid, p.32).

Sensory diseases and disorders provide many examples of conditions such as myopia, astigmatism and mild presbyacusis, which seldom proceed beyond impairment. However, as will now be shown, the consequences of sensory diseases and disorders in their more serious manifestations are particularly amenable to clarification by a judicious use of the ICIDH terminology.

Visual Disorder and its consequences

Within the consequences of disorders which affect vision, the work of August Colenbrander (to whom tribute is paid in the Introduction to the ICIDH) seems particularly important. He has suggested that the terms 'visual disorder', 'visual impairment', 'visual disability' and 'visual handicap' should not be used synonymously, but always with a distinct reference (Colenbrander, 1977). He proposes that 'visual disorder' should only be used

to provide a summary description of the state of 'the components of the visual system'. Similarly, 'visual impairment' should only be applied to 'the overall function of the visual organ'; 'visual disability' only to 'the total abilities of the person', and 'visual handicap' only to 'the need for extra effort because of visual loss'. Elsewhere, Colenbrander (1976) presents this terminology in the form of the conceptual scheme shown in Figure 4.3.

The impression of an almost one to one correspondence between this scheme of terminology and that proposed in the ICIDH is heightened within a discussion of Colenbrander's ideas by Peterson and his colleagues (1978). They present the above terminology in the form shown in Figure 4.4.

Figure 4.3 Relationship between components of visual performance (Colenbrander)

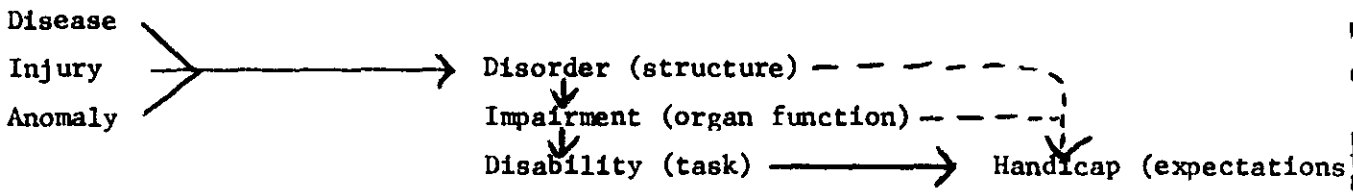


Figure 4.4 Concepts underlying measures of visual loss and performance

Concept	Proposed Term
Deviation from normality in the structure of the eye	Disorder
Limitation in the overall function of the eye	Impairment
Limitation in the ability of an individual to perform specific tasks	Disability
Limitation in the social functioning of an individual	Handicap

Colenbrander was particularly concerned to draw attention to the consequences of using a terminology in line with that of the proposed ICIDH both for classifying and for measuring visual ability and loss of vision. He pointed out that the definition of the four parameters of visual loss

presented in Figure 4.4 enables us to proceed to better descriptions than have been available hitherto of the role of ophthalmology and ophthalmologists in helping individuals to cope with visual impairments:

> 'Medical and surgical care obviously is the primary domain of the ophthalmologist. Its impact is on visual disorders and on visual impairment, but medical care, traditionally, does not address the area of visual disability and visual handicap. The use of visual aids is the domain of ophthalmologists, ophthalmic assistants, and other workers. Visual aids cannot change the pathology, but they can reduce impairment and significantly enhance abilities. A third area of support [is] patient education .... This category embraces a wide variety of individuals, including classroom teachers, mobility instructors, vocational advisors, and psychological counsellors .... Comprehensive low vision care cannot be provided by any one professional in isolation'. (Colenbrander, 1977).

Colenbrander summarised his scheme of terminology and its application to the care of patients with disorders of vision by means of the table shown in Figure 4.5. Though the information given in this Figure overlaps with Peterson et al's presentation in Figure 4.3, the suggested scope of the various agents in treatment and rehabilitation is a new and important feature.

Figure 4.5 Dimensions of Visual Performance

	Visual Disorder	Visual Impairment	Visual Disability	Visual Handicap
Description	Pathologic components of visual	Reduced function of visual system	Reduced abilities of individual	Need for extra effort Reduced independence
Area affected	Refracting media Retina Optic nerve Brain	Visual acuity Visual field Binocular vision Colour vision Night vision	Reading skills Mobility, orientation Daily living skills Vocational skills	Physical independence Mobility Economic independence Employment Social integration
Treatment	← Medical, surgical care →			
		← Visual aids ——→		
			← Patient education ——→	

Auditory disorder and its consequences

If the ICIDH and Colenbrander's schemes are applicable to the consequences of disorders of vision, it is obviously possible to devise and apply a similar scheme to disorders of hearing. Again the most obvious difference made by using the scheme in which auditory disorder, impairment, disability and handicap are distinguished is that a fair degree of precision in writing will be called for. It will be inappropriate to vaguely refer to aspects or planes of the consequence of auditory disorder as 'handicaps' or to label persons with impaired hearing as 'handicapped' unless specific disadvantages are incurred and identified (Clark, 1977).

Again the tasks of agents of rehabilitation from otologists through audiology technicians to hearing aid therapists are more clearly defined. The medically trained otologist, like his counterpart in Colenbrander's scheme,

the ophthalmologist, deals with the first links in what might be a long chain of significant events. The hearing aid technician will co-ordinate treatment, particularly the supply, fitting and use of aids within the area of auditory impairment and the disability consequent on it, while hearing aid therapists, teachers of the hearing impaired and, indeed, a wide range of voluntary helpers will work chiefly with persons who experience the handicaps consequent on the impairments and disabilities which have occurred. Taylor (1977) made the same point in a more general way when he referred to Wood's draft scheme in these words:

> '... if it is accepted that the major practical benefit to be gained from a clear description of the process of disease or injury leading through to social disadvantage is that it may help to reveal to what extent and in what way impaired individuals' problems may be solved or reduced by complementary medical and social assistance, then (Wood's scheme of terminology) is, on balance, the most appropriate one'. (op. cit. p. 6).

Avoiding stigma

From a close reading of the WHO presentation there is no difficulty in gleaning several other important advantages of making a vigorous attempt to use the ICIDH terminology. On the subject of disability, it is suggested in the discussion of ICIDH terminology (WHO, 1980) that 'disability is concerned with the practical in a relatively neutral way', ie that it is concerned with what a person does do not with what he might do, could do or should do: 'it is not concerned with the absolute, the ideal or with any judgements as to whether a person could do such a thing if he wanted to'. It follows that declarations about a person's disabilities in the ICIDH sense need to be framed with considerable care. If, for instance, we say that someone is disabled we are not saying the same thing as if we say that someone has a disability. The ICIDH commentary expresses the advantage of the latter phraseology thus:

> 'statements phrased in terms of <u>being</u> rather than <u>having</u> tend to be more categorical and disadvantageous. Thus to say that someone is disabled, as if this were an adequate description of that individual, is to risk being dismissive and invoking stigma'. (Ibid, p.28).

In other words, in taking care about how we express ourselves on the subject of the consequences of disease, we are not only likely to make ourselves clear to colleagues, but we are also likely to avoid unnecessary occasions of offence through inadvertently stigmatizing people who have disabilities or handicaps. Nygard (1976) draws attention to a common occasion of stigma when she quotes the Norwegian poet, Bekke:

> 'I used to be Mrs Lund with a stiff hip.
> Now I am a stiff hip called Mrs. Lund'.

CHAPTER FIVE

SOME GENERAL PRINCIPLES OF CLASSIFICATION RELATING TO HEALTH CARE

Classification

In most discussions of health care 'classification' is the term most commonly used to denote the whole process of forming frameworks and schemes within which diseases and their consequences (or people suffering from these) can be identified, categorised and evaluated. The purpose of this process is, of course, the formulation of policy or the analysis how an existing system is working.

This process of classification may be qualitative or quantitative: a distinction which may itself be a source of confusion. It helps if the process of putting entities into designated classes is termed 'assignment'.

> 'A classification allocates entities to initially undefined classes so that individuals in a class are in some sense close to one another. The process of choosing which of a number of defined classes a new entity should be allotted to is better called ''identification'' or ''assignment''.' (Cormack, 1971).

Another rather more local problem with words occurs in Britain within customary Department of Health and Social Security (DHSS) usage. At the outset of the project described in the present study, the author was confused by colleagues who persisted in using the noun 'classification' to refer specifically to any measure, index, scale or process by means of which persons experiencing the consequences of disease or disorders can be allocated to 'severity' groups. It did not help that this specific usage, admittedly of considerable importance, was usually associated with a vague use of terms such as disability and handicap. Obviously, classification can be quite properly used in this sense, but should not, even within

the work of the DHSS, be wholly confined to it. In fact, in the present chapter, only qualitative classifications which allow for the 'assignment' of entities to previously specified groups are discussed.

Classification of disease consequences

In recent years, as the description of the ICIDH already given in Chapter Four shows, there has been a growing awareness of the need for a classification of the consequence of disease rather than of disease itself. Further some workers have described the properties which such a classification might have. Thus Agerholm (1975a) looked for a system which would enable

> '... both handicaps and handicapped people [to be] correctly identified, recorded and analysed in a terminology which is valid and which is intelligible to the wide range of people, including the handicapped themselves who need a common language ...'

Similarly, Topliss (1978), who commends Agerholm's attempt at such a classification, stressed the need for a classification which is 'generally accepted and simply operated'. She also combined this call for acceptability and simplicity with a discussion of why it is that there is still an urgent need for a definitive classification of the consequences of disease. She suggested that for too long the tendency has been to classify disabled people mainly according to their medical condition, pointing out that this is inadequate because it is peoples' disabilities which affect their capacity for normal living, whether in the sphere of personal care, employment, family relationships, social activities or leisure. The example she gives is obvious but apt: a victim of a disorder such as cerebral palsy 'may have minimal brain damage, be able to walk and talk normally and be of normal intelligence, or he may be utterly helpless, incontinent and mentally defective' (op. cit., p 123).

The need for a classification of disease consequences together with some general ideas of what it might do and who might use it have therefore been clearly perceived. However, some basic principles need clarification before the ideas can be effectively realised.

Basic principles

The study of the basic principles under which 'qualitative' classificatory systems are devised is often referred to as 'taxonomy' or, more precisely, following Gregg (1954), as 'methodological taxonomy'. Gregg's approach is distinguished by the way in which he links mathematical and philosophical approaches to taxonomy. He is concerned to draw attention to 'set' theory as a discipline which, lying on the borderline between elementary logic and elementary mathematics, is particularly relevant to clarifying problems of taxonomy. More accessible to the non-specialist, however, are less formal approaches to the principles of taxonomy such as that described in a paper by Hempel (1961). In spite of its largely theoretical approach and its philosophical standpoint, this paper is valuable to those working in health care because it was presented at a work-conference of medical personnel and its thesis was amplified by them in recorded discussions.

Hempel suggested that the division of a given subject or 'universe of discourse' into classes proceeds by the identification of sets of concepts which single out similarities and differences among the entities to be classified. Usually, he remarked, there are several different ways of dividing any universe of discourse, since the initial choice of different sets of concepts will lead to different similarities and differences being chosen as criteria for forming classes. Hempel went on to discuss how the similarities and differences are to be chosen. He particularly emphasised the need for 'objective' and 'reliable' criteria of classification. In his

argument the required criteria are described as objective, because they should produce the same categorisation of entities no matter which classifier applies them: similarly, they are described as reliable because they should produce the same categorisation when applied to the same entities on different occasions.

Hempel also put forward the idea that 'good' classification will appear to 'carve nature at the joints', i.e. the classes formed will, in the view of experts on the universe of discourse under consideration, correspond to observable manifestations of the phenomena being classified or with generally accepted theoretical principles. The most important of these particular principles is that the entities within a class should be more similar to each other in terms of the selected criteria than to the entities in other classes. Hempel cited the periodic table of the elements as perhaps the supreme example of a classification with the property of carving nature at the joints. Its arrangement, as even the most elementary chemistry texts makes plain, corresponds both to readily observed regularities in the physical and chemical properties of the elements and their compounds, and to the way in which the atoms of the elements can be modelled in terms of an underlying electronic structure.

Four principles

Another clear exposition of the defining characteristics of a good system of classification is that of Lazarsfeld and Barton (1951). They set out the general requirements of such a system under four heads:

> '1. Articulation: The classification should proceed in steps from the steps from the general to the specific, so that the material can be examined either in terms of detailed categories or of broad groupings, whichever are more appropriate for a given purpose.

2. Logical correctness: In an articulated set of categories those on each step must be exhaustive and mutually exclusive. When an object is classified at the same time from more than one aspect, each aspect must have its own separate set of categories.

3. Adaptation to the structure of the situation: The classification should be based on a comprehensive outline of the situation as a whole - an outline containing the main elements of the situation which it is important to distinguish for purposes of understanding, predicting, or policy-making.

4. Adaptation to the respondents' frame of reference: The classification should present as clearly as possible the respondents own definition of the situation - his focus of attention, his categories of thought'. (op. cit. p.156f).

Adaptation to situation and respondent

The last two principles appears worthy of a more extended comment. Sometimes, as with the example of the periodic table, it might just be possible to work on the assumption that there actually exists some basic reality external to ourselves and that this basic reality so structures the nature of the situation that the essence of categorisation is to approach that structure as nearly as possible. The more usual standpoint today, within the natural sciences as much as outside them, is that 'reality' is negotiated; that there is no such thing as the 'essential nature' of a situation or problem. How one categorises, therefore, defines the situation or the problem just as the operations one carries out defines the entity one is dealing with in an operational definition. Similarly, the basis on which one categorises depends on ones own 'subjective' interpretation of reality - which is, presumably, a combination of experience, background, attitudes etc., together with the current definitions and categories used by colleagues and society as a whole. To give a simple example, a social worker might well define the main determining factor in the delinquency of

a particular child as 'maternal deprivation', whereas the erring child's father is probably more likely to find that factor in how own low wages so that his wife has to work as well. Actually, this example is interesting because it shows how the theories and categories of the trained professional are usually less general and more focussed than those of the lay person. A professional economist would probably find a tighter version of the father's explanation more congenial to his own approach to the situation.

Under this analysis the categorisation of a situation and the approach taken to the solution to a problem are bound up together in the same value-judgement system. A 'good' classification therefore reveals this system and the assumptions it is built upon and within these constraints leads to a 'good' solution; it acts rather more as if it were sharpening the focus on a TV set than enabling one to select the right channel.*

A fifth principle

A close reading of Lazarsfeld's and Barton's paper shows that they would be happy to add a fifth determinant of a good classification to those listed above on pages 58 and 59: a classification should be adapted to those by whom it is to be used.

One way in which this principle can be satisfied to some extent is by paying attention to the third principle and adapting the classification to the

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*I am indebted to Ms Hazel Canter, Senior Research Officer, Social Research Branch, DHSS for reminding me of the ideas expressed in this section, and especially for the examples in it.

'situation' by focussing on the concerns of the intended classifier. However, it may happen that a classifier is an expert on the subject matter of the classification but still feels lost when confronted by a complex system of classification. Hence Lazarsfeld and Barton drew attention to the need for designing a classification in such a way that its users can be trained in a reasonably short time to perform classification with a high degree of agreement. They suggest that not every user of a classification should be expected to be an expert in both its subject matter and the principles of classification. Most occasional users of a classification need rules for assignment; instructions perhaps, telling him what to look for as a basis for making assignations to the classes.

The Risks of classification and assignment

A final general point about classification can be drawn from the work of Cromwell and his colleagues (1975). Like Hempel they wrote from a standpoint in the philosophy of science, but the context of their writing is a well-researched study of the classification of 'exceptional' children in the United States (Hobbs, 1975). (Exceptional children are those children who require unusual educational treatment whatever the reason, including both impairment and very high ability).

Cromwell and his colleagues investigated the views of certain interest groups who were suggesting that classification (assignment) can result in discrimination against categorised groups with a consequent loss of freedom for those groups. In fact, the whole project began from a conviction that the classification systems for exceptional children which were in operation in the United States in the late 1960's tended to discriminate against these children relative to 'normal' children. It was even thought that it might be necessary to abandon the classification of exceptional children altogether.

In the event, the researchers undertaking the study decided that this action would be altogether too drastic. They came to the conclusion that it was possible to devise quite detailed classification systems for these children in which the advantages would outweigh the disadvantages. The sort of balance achieved is indicated in the following passage:

> Children who are categorised and labelled as different may be permanently stigmatized, rejected by adults and other children, and excluded from opportunities essential for their full and healthy development. Yet categorisation is necessary to open doors to opportunity: to get help for a child, to write legislation, to appropriate funds, to design service programs, to evaluate outcomes, to conduct research, even to communicate about the problems of the exceptional child. (Hobbs, 1975, p.3).

Elsewhere, in quite a different context, though one which is more obviously relevant to the subject of this study, Wood (1975) has also defended the practice of forming classifications and assigning people to them against those who are concerned that classification too often engenders stigma against those who are suffering the consequences of disease or other kinds of disadvantage:

> 'Unless categories can be identified, one is really unable to begin to count, and until counting is possible one cannot know how big the problems are or deploy resources intelligently in an endeavour to control the problems'. (Wood, 1975, p.5)

Nor, it might be added, can one identify what one regards as the essential nature of the problems faced, the essence of their solution or the relevance of that solution to the individual.

It seems, therefore, that there is no escape from the dilemma. If one classifies, then a risk is being taken that the system developed so carefully

by practitioners to meet particular purposes of understanding and intervention will become part of an unbeneficial broader 'public' usage. This may then result in discrimination against categorised groups with a consequent loss of freedom for the members of that group. However, if one does not classify, then nothing will be done for good as well as for ill. In any case, that the broader public usage will be unbeneficial is only a possibility or at worst a probability; it is not a certainty. At the very least there is usually a considerable time lag before official usage becomes public. An example of this is the DHSS use of the term 'Young Physically Handicapped' to cover those in the age range of 16-65 years who have impairments. Not surprisingly, this does not yet appear to have been assimilated by health care personnel, let alone the general public. In addition, the process of labelling does not always lead to more negative attitudes to the group labelled. What happens during public usage is often unpredictable. For example, when the term 'autistic' first became used by professionals, parents of 'mentally subnormal' (then in use) children often adopted autistic as a 'nicer' way of describing them. (Barnitt, 1978).

Statistical techniques of Classification

In recent years there has been an increase in the use of what might be called 'automatic' techniques of classification. In these techniques, classes of entities are formed empirically, i.e. account is taken only of numerically coded characteristics of the entities to be assigned when the classes are formed. The result is an empirical classification, i.e. we do not so much start with a previously-designed classification and assign entities to it, rather we start with the entities and build up the classification on the basis of their main characteristics.

At the outset of a review of this approach, MacNaughton-Smith (1965) has described its use as representing a trend in taxonomy characterized by its movement from being a 'semi-intuitive art' towards the use of objective methods using numerical techniques applied by means of computers. The approach is increasingly being applied to classification in the social sciences generally, and has found application recently in certain aspects of health-care. A few recent attempts to apply 'cluster analysis', one of the most widely-used techniques exemplifying the approach, are described in Chapter Seven.

At the present time it seems likely that most health-care workers and administrators will not be very familiar with cluster analysis and similar techniques for assimilating large quantities of data. This is only to be expected as most of the studies so far undertaken, including those to be described in a later Chapter, are predominantly research exercises whose full practical applications remain to be explored. Hence it may be that the best attitude to take to these statistical techniques of classification is to suspend judgement until their practical application, or lack of it, has been demonstrated. At the same time, there are certain principles of judgement, outlined by statisticians themselves, which can be applied to te results of the exercised to test the methods which have been devised.

MacNaughton-Smith (op. cit.) discusses these principles. He suggests that there are two simple criteria of a 'good' statistical classification which are accepted by nearly all writers. The first is 'internal stability' ie the classification will not be altered significantly by the addition of new data, either in the form of further observations on the entities being classified or in the form of an enlargement of the initial set of entities. The other criterion is 'external applicability', ie the classification

obtained should lead to hypotheses that withstand testing on new data. As stated here, the criteria seem somewhat alike, and MacNaughton-Smith shows that in terms of probability theory the two criteria are in fact equivalent. (op. cit., p.7f).

In a more recent review of modern procedures of statistical classification, Cormack (1971) has emphasised the danger of indiscriminately applying 'automatic' methods such as cluster analysis to the task of summarising multi-variate data without checks of the kind mentioned above. In the discussion which followed the presentation of his paper, other statisticians suggested rules and checking procedures which could profitably be kept in mind both by those undertaking cluster analysis and by those who, without much knowledge of its principles, attempt to assess its results. The advice seems generally to urge caution in both sides. Typical advice is that given elsewhere by Bartko, Strauss and Carpenter (1971) who have described processes for clustering psychiatric patients thus

> In the process of attempting to cluster ... many decisions regarding the analysis of the data ... are made. Because these decisions affect cluster output, it is essential to define the nature of the choices made, their potential influence on clusters, and to develop criteria for selecting one procedure over another.

Similarly, Jardine and Sibson (1971) have suggested that before attempting an automatic classification procedure, it is helpful to decide whether or not the task being undertaken is one in which there is an external criterion against which the outcome can be assessed. If there is such a criterion then making judgements about method and results is relatively easy - how well does it work? When there is no obvious external criterion the implication of Jardine and Sibson's discussion appears to be that there is no alternative for non-statisticians to that of consulting their

specialist colleagues who can then apply their understanding and experience of the mathematical properties of the suggested methods to make an assessment of the validity of the procedure used.

CHAPTER SIX

THE CLASSIFICATION OF DISEASES AND OF THEIR CONSEQUENCES

The International Classification of Diseases

Some of the principles of taxonomy as they relate to classification within medicine are discussed in the manual describing the use of the various revision of the 'International Statistical Classification of Diseases, Injuries, and Causes of Death', to give this well-known system of disease classification, usually known as the International Classification of Diseases (ICD), its full title. The main principle on which this system has been constructed appears fairly straightforward and has not changed over the years: it brings together in groups diseases that have considerable affinity on the basis of agreed clinical and pathological observations.

The Introduction to the ICD pays particular tribute to William Farr who, when he was Registrar General of England and Wales, realised the need for a sound classification of diseases. In fact, his Sixteenth Annual Report (1856) is quoted in the ninth and earlier revisions of the ICD to draw the readers attention to the fourth of the determinants of a 'good' system of classification referred to in the previous chapter - that it should be adopted to the respondent's frame of reference:

> 'Classification is a method of generalisation. Several classifications may, therefore, be used with advantage; and the physician, the pathologist, or the jurist, each from his own point of view, may legitimately classify the diseases and the causes of death in the way that he thinks best adapted to facilitate his enquiries, and to yield general results.' (WHO, 1977, p.viii).

The focus of the ICD classification is, however, medical; the physician and the pathologist will be more likely to use it than the lawyer or the administrator. In other words, like all classifications, the ICD has a limited range of convenience. It is suitable for systematically describing disease phenomena as perceived by members of the medical profession. A tendency which has been difficult to resist has been that of forcing data from within the broader framework of 'health care' generally into this powerful and useful model. The ICD is now quite properly used for purposes, especially record-keeping, outside the scope originally envisaged for it, but there are limits to its versatility. Other classifications, some of which are outlined in the ninth revision of the ICD, are required when phenomena outside or on the fringes of disease phenomena need categorization.

The ICD also provides a very good example of the first of Lazarfeld's and Barton's classification principles outlined in the previous chapter – that of 'articulation': proceeding in steps from the general to the specific. Lazarfeld and Barton (1951, p.157) observe that articulation solves the dilemma of having to choose between too few groupings for precision or too many for clarity and convenience. Figures 6.1 and 6.2 (p. 69) give an example of how the ICD starts with a few broad disease categories, and how these are broken down by stages so that the classification can be used at different levels of detail. The example, chosen for its brevity, relates to the first two sub-sections, coded 740 and 741, of Section XIV of the Classification. (This Section deals with 'Congenital Abnormalities'.) Figure 6.1 shows how Section XIV is classified topographically, whilst Figure 6.2 shows how sub-sections 740 and 741 are articulated by means of a fourth digit.

FIGURE 6.1 CODING OF SECTION XIV OF THE ICD

XIV CONGENITAL ANOMALIES

740 Anencephalus and similar anomalies
741 Spina bifida
742 Other congenital anomalies of nervous system
743 Congenital anomalies of eye
744 Congenital anomalies of ear, face and neck
745 Bulbus cordis anomalies and anomalies of cardiac septal closure
755 Other congenital anomalies of limbs
756 Other congenital musculoskeletal anomalies
757 Congenital anomalies of the integument
758 Chromosomal anomalies
759 Other and unspecified congenital anomalies

FIGURE 6.2 CODING OF SUB-SECTIONS 740 AND 741 OF THE ICD

740 Anencephalus and similar anomalies

740.0 Anencephalus

Acrania
Amyelencephalus
Hemianencephaly
Hemicephaly

740.1 Craniorachischsis

740.2 Iniencephaly

741 Spina bifida

Excludes: spina bifida occulta (756.1)

741.0 With hydrocephalus

Arnold-Chiari syndrome

Any condition in 741.9 with any condition in 742.3

741.9 Without mention of hydrocephalus

Hydromeningocele (spinal)
Memingocele (spinal)
Meningomyelocele
Myelocele
Myelocystocele
Rachischisis
Spina bifida (aperta)
Syringomyelocele

Wood (1978) has discussed the principles of the ICD since he needed to draw on similar ideas for his draft version of the ICIDH. He remarked that in selecting a scheme of classification one is always involved in balancing gains and losses. The choice, he wrote, is almost wholly dependent on the purpose for which the classification is required: 'to evaluate a classification, one need only consider its conformity to a single criterion, that of utility - does the taxonomy do what you want it to do?' He pointed out that, in this respect, because of pressure from people with contingent interests, the ICD has become a compromise kind of classification. While it was originally developed as a means of facilitating comparability in mortality studies, now it is widely used for records of all kinds.

Wood also draws attention to several conflicts in priority which claim attention whenever the ICD is revised - 'whether to proceed primarily according to the greatest reliability of information, such as is reflected by anatomical localisation, or to give precedence to aspects like aetiology or pathology'. For this and similar reasons it seems that parts of the ICD, however much they have been revised, have tended to lack credibility with specialists in certain diseases. For example, pulmonary tuberculosis has always been classified in the ICD with infective diseases: quite properly so, since the basis for forming this group and classifying within it is the aetiology of the disease. However, many specialists of diseases of the respiratory system would prefer pulmonary tuberculosis to be classified among those diseases. Again, quite properly so, since the basis for forming this group and classifying within the respiratory diseases is the site of the disease.

Wood's comments about conflicts of priority in the ICD seem to reflect a clash between the second and third of Lazarfeld's and Barton's four principles. For logical correctness, classes should be mutually exclusive, but, if one 'adapts to the structure of the situation', certain diseases could quite properly be classified in more than one section. This kind of dilemma has arisen because the main sections of the ICD have never been formed on the same basis. Some diseases are classified according to cause, others according to site, and, under the rules by which the ICD operates, a decision usually has to be made to put a particular disease in one section and not in another. Elsewhere, Wood (1976) has described how this mixed classification system works:

> 'In most sections of the Revision of the ICD the primary axis is topographical . . ., less frequently it is etiological . . . or situational. In other sections, still other primary axis are used, reflecting the fact that the ICD is a compromise and an attempt at producing a pragmatic classification that can be used for a variety or purposes.'

In the most recent (ninth) revision of the ICD extensive changes have taken place. These have been summarized by Kupka (1978) who suggests that the main reason for them is to adapt the classification for the many non-statistical uses, such as medical record keeping, to which the ICD is increasingly being put.

The International Classification of Disease Consequences

The ICIDH, whose basic terminology has been discussed in previous chapters, is of more direct interest and use than the ICD to people working in the areas of rehabilitation, provision of benefits, long-term health care in the community, etc. Its intended purpose is summarized in the manual (WHO, 1980) as one of providing 'more appropriate categories than are at present available for generating those data which will enable health care systems to be evaluated. The three major needs which the classification will supply by virtue of having these properties are stated to be:

> i. the production of statistics on the consequences of disease
>
> ii. the collection of statistics relevant to the utilization of services
>
> iii. indexing and case-record retrieval according to the attributes identified in the classification. (Ibid, p.18)

A central feature of the ICIDH is that it consists of three separate and distinct classifications, one for impairments, one for disabilities and one for handicaps. As was explained in Chapter Four (see especially Fig 4.2, p.43) these concepts can be treated as consecutive elements in peoples' experience of the consequences of disease. However, they are not classified in the same way. Thus the taxonomic structure of the classifications of impairments and disabilities, is described as 'hierarchical' (i.e. articulated) in that meaning and usefulness are preserved even if the codes are used only in abbreviated forms. Handicaps are classified differently as Figure 6.6 (p. 75) will show.

FIGURE 6.3

OUTLINE OF MAIN ICIDH CATEGORIES OF IMPAIRMENTS

1. Intellectual Impairments
2. Other Psychological Impairments
3. Language Impairments
4. Aural Impairments
5. Ocular Impairments
6. Visceral Impairments
7. Skeletal Impairments
8. Disfiguring Impairments
9. Generalised, Sensory and Other Impairments

FIGURE 6.4

OUTLINE OF MAIN ICIDH CATEGORIES OF DISABILITIES

1. Behaviour Disabilities
2. Communication Disabilities
3. Personal Care Disabilities
4. Locomotion Disabilities
5. Body Disposition Disabilities
6. Dexterity Disabilities
7. Situational Disabilities
8. Particular Skill Disabilities
9. Other Activity Restrictions

Figures 6.3 and 6.4 outline the proposed classifications of impairments and disabilities respectively, but only as far as the first digit of the classifications. Figure 6.5 shows the 'articulation' as far as the second digit of category 1 impairments. This category, designated 'Intellectual Impairments' is sub-divided into Class 10 ('one-zero', not 'ten') 'Profound mental retardation', Class 11 (one-one) 'Severe mental retardation', etc. Theclassifications of impairments and disabilities are also, like the ICD, exhaustive; any impairment or disability can be classified in them somewhere, just as any disease can be classified in the ICD.

FIGURE 6.5

ARTICULATION OF INTELLECTUAL IMPAIRMENT CATEGORY

1. INTELLECTUAL IMPAIRMENTS

Impairments of intelligence 10-14

10. Profound mental retardation

11. Severe mental retardation

12. Moderate mental retardation

13. Other mental retardation

14. Other impairment of intelligence

Impairments of memory 15-16

15. Amnesia

16. Other impairment of memory

Impairments of thinking 17-18

17. Impairment of flow and form of thought processes

18. Impairment of thought content

19. Other intellectual impairments

Classification of handicaps in the ICIDH

In the ICIDH, handicaps are not classified according to individuals or their attributes, but according to the circumstances in which disabled people are likely to find themselves. Indeed, the theoretical position taken, that disadvantage is best thought of in terms of specified 'survival roles' (Maslow, 1954) reflecting ' . . . the most important assumptions made about the existence and survival of the individual as a social being', seems to preclude exhaustive categorisation. In constructing the classification, decisions have been made both as to which survival roles are significant and which 'roles' can be designated 'survival'. The categories or dimensions of handicap proposed for the ICIDH are shown in Figure 6.6.

FIGURE 6.6

OUTLINE OF ICIDH DIMENSIONS OF HANDICAP

1. Orientation Handicap
2. Physical Independence Handicap
3. Mobility Handicap
4. Occupational Handicap
5. Social Integration Handicap
6. Economic Self Sufficiency Handicap
7. Other Handicaps

IDH
Details of the/classifications

In the first chapter of the ICIDH, entitled 'The Consequences of Disease', the three classifications and their general characteristics are described in more detail. On the classification of impairments it is suggested that the primary aim has been to supply detail at no higher a level than need be to define the content of classes precisely. The most important feature influencing the intervention or support the individual is likely to need is to be identified first. This usually requires two digits only, sometimes supplemented by a third decimal digit. However, a fourth digit is available, primarily to record the consequences of amputations. Provision is also made, as in the latest revision of the ICD, for multiple coding and for the use of special combination categories. In terms of the main purpose of the classification, it is suggested that the 'I' (impairments) code would probably be most used as an 'indicator of unmet needs' or as a 'classification of health related problems that an individual is likely to encounter'. (WHO, 1980, p. 37).

The classification of disabilities ('D' code) is similarly presented in terms of its purpose - to encompass 'the more important behaviours and activities associated with everyday life' and to record 'the interface between the individual and his environment in such a way as to display his potential'. Hence it is suggested that 'perhaps the ideal aim for the D code would be to present a profile of the individual's functional abilities, as determined from what disabilities were present, in such a way that reciprocal specification of the environment allowed matching with the individual's capabilities' (ibid). An example of this ambitious but practical aim is given in the context of job placement and vocational rehabilitation. It is suggested that similar uses of the D code could be devised for school placement, for rehousing the disabled, and for identifying vulnerability in the elderly.

The D code is also designed for expansion to allow for conventional global assessments of severity of disability as by means of instruments measuring activities of daily living such as those to be discussed in Chapter Nine. This seems essential because disabilities reflect failures in actual accomplishments - what a person cannot do - and gradation in accomplishment is to be expected. Provision has been made for recording degrees of disability by means of an additional supplementary digit with full guidance on its use.

Just as the classification of disabilities is intended to indicate a person's person's potential, so the classification of handicaps (H code) is intended to indicate the extent to which that potential is realised. The problem is that handicaps or disadvantages, even more than disabilities, are related

to the particular culture in which the individual lives. Hence the aim in arriving at a basis for the classification was to identify fundamental accomplishments 'related to the existence and survival of man as a social being and . . . expected of the individual in virtually every culture'.

As was mentioned on p. 74 the key dimensions of accomplishment of individuals are designated in terms of Maslow's survival roles. Obviously, the designations of the survival roles, and indeed the notion of the use of these as appropriate for the designation of handicap states, could easily be criticised from both philosophical and biological standpoints. However, they appear to have at least two advantages. First, they are positive: the individual's advantages rather than his disadvantages are indicated. (It is a possible weakness of the D code that it indicates disabilities rather than abilities, a profile of the latter having to be deduced from the former.) Secondly, as is pointed out in the manual(op.cit,p.38), the scheme allows ample scope for expansion to new dimensions which indicate 'higher' levels of need than those suggested by Maslow.

The basic dimensions in the handicap classification are six in number as Figure 6.6 shows. The intention is that individuals will be classified according to degree of handicap along each of the dimensions. Hence the classification is obviously multidimensional and within each dimension quantitative description can be attempted.

At the end of each of the three classifications there is helpful guidance on assignment of the kind suggested as important under the 'fifth principle' discussed in the previous chapter. For impairment, besides a reminder that the level of details to be recorded in terms of articulation is a matter of choice for the user, it is suggested that the code can best be used as a check-list to be applied to each individual. Some of the problems in recording severity of impairment are considered.

For disability, the notes for guidance are more complex, mainly because considerations of severity are more important. Thus disability, though it could, like impairment, be considered as a threshold phenomenon, is, as suggested earlier, probably better considered in terms of deficit in performance for which gradation can be expected. Further, the degree of disability and, possibly, whether disability is identified in the first place, could well vary according to the method of ascertainment used:

> '... care will be necessary in regard to variation resulting from the use of clinical assessment, functional tests (including the activities of daily living), or questionnaires .... caution is also necessary in appreciating the manner in which disability may be established in different contexts - a professional medical definition based on a physician's judgement, a behavioural definition derived from performance of selected activities, or a legal definition, framed in terms of eligibility for various benefits.' (WHO, 1980, pp.16 & 17.)

CHAPTER SEVEN

SOME OTHER CLASSIFICATIONS WITH GENERAL RELEVANCE TO HEALTH CARE

A Nomenclature and Classification of Handicaps

About the time that Wood's draft proposals for a classification of impairments, and handicaps were put forward, the British rehabilitationist, Dr Margaret Agerholm, whose suggestions for a 'handicap' terminology have already been mentioned (pp.30-32), drew up a scheme describing 'A Nomenclature and Classification of Handicaps' (Agerholm, 1975a, 1975b). Her starting point was dissatisfaction with the widespread lack of clarity in the terminology of disease consequences. She was aware that, while the ICD is capable of providing a comprehensive classification of diseases for record-keeping and statistics, there was nothing comparable for the consequences of disease:

> 'Administrators, sociologists, statisticians, lawyers, planners of social services and cash benefits, designers of equipment and special buildings, all need a basic language in which to collect and present information about handicaps and handicapped people, so that they can consider best how to meet the needs which handicaps create for the individual and for the community.' (1975a).

Agerholm's documentation of the need for a new terminology of the consequences of disease and of the inadequacy of many of the classifications in use when she wrote is thorough. Her remarks relating to the Department of Employment's 'A to Z' system* of classifying disabled people imply that a classification ought to be designed with a rational model of the situation in which it is to be used in mind. She suggests, therefore, that the structure of a classification should not depend on some accidental property of an element extraneous to that situation, such as that the Roman alphabet contains 26 letters:

---

*It seems likely that the Employment Medical Advisory Service will shortly recommend a new system, possibly based on the WHO work (Edwards, 1980).

'... the Department of Employment keeps a register of "the disabled", whose classification, inherited from a less-well-informed past, is based on a confusion of anatomical, topographical and disease groupings which have little relevance to the Department's present duties both to provide training and placing procedures for a very different handicapped population, and to develop work opportunities for them in very different social and work situations from those which the groupings were originally selected.' (Ibid)

Agerholm expressed her aim in devising her own version of a classification of disease consequences as producing what is, as far as possible '... a comprehensive representation of all the discrete components of 'handicap' /put/ into a grouping which is simple enough for a perspective view, and at the same time, allows analysis of special areas at the high degree of magnification which individual specialties need'.

The basic structure of the Classification is shown in Figure 7.1, p.81. The structure is 'fixed' in that branching structures analysing each component of 'intrinsic handicap' can be added to the basic structure shown in order to allow for a scrutiny of the handicaps of different groups of people. In a paper delivered at a meeting of specialists of the Continence Society, Agerholm (1975c) has illustrated how this might be done in one particular specialist medical context. The classification has, however, been found useful in contexts which are less specifically medical. It was used, for instance, as a basis for a survey of the needs of elderly and disadvantaged people in the City of London (1976), and for a survey of the prevalence of 'handicap' in Northern Ireland. Also Bradshaw (1978) has used it as the starting point for a scale which he has developed to measure the degree of disability (in ICIDH terms) of impaired children.

FIGURE 7.1 CLASSIFICATION OF INTRINSIC HANDICAPS (AFTER AGERHOLM)

Handicap		Handicap components
1.	Locomotor	a. Impaired mobility in environment.
		b. Impaired postural mobility.
		c. Impaired manual dexterity.
		d. Reduced exercise tolerance.
2.	Visual	a. Total loss of sight.
		b. Impaired visual acuity (uncorrectable).
		c. Impaired visual field.
		d. Perceptual defect.
3.	Communication	a. Impaired hearing.
		b. Impaired talking.
		c. Impaired reading.
		d. Impaired writing.
4.	Visceral	a. Disorders of ingestion.
		b. Disorders of excretion.
		c. Artificial openings.
		d. Dependence on life-saving machines.
5.	Intellectual	a. Mental retardation (congenital).
		b. Mental retardation (acquired).
		c. Loss of learned skills.
		d. Impaired learning ability.
		e. Impaired memory.
		f. Impaired orientation in space or time.
		g. Impaired consciousness.
6.	Emotional	a. Psychoses.
		b. Neuroses.
		c. Behaviour disorders.
		d. Drug disorders (includes alcoholism).
		e. Antisocial disorders.
		f. Emotional immaturity.
7.	Invisible	a. Metabolic disorders on permanent therapy (eg diabetes, cystic fibrosis).
		b. Epilepsy and other unpredictable losses of consciousness.
		c. Special susceptibility to trauma (eg to pressure sores, to haemorrhage).
		d. Intermittent prostration (eg vertigo, migraine, asthma).
		e. Severe pain disorders.
8.	Aversive	a. Unsightly distortion or defect of body.
		b. Unsightly skin disorders or scarring.
		c. Abnormal movements of body (athetosis, etc).
		d. Abnormal smell or noise.
9.	Senescence	a. Reduced 'plasticity' or ageing process.
		b. Slowing of physical or mental function of ageing process.
		c. Reduced recuperative powers of ageing process.

Source Agerholm 1975 a. References 26 and 38 and Taylor 1977

This last mentioned use of Agerholm's classification - as the basis for a scale of disability rather than of handicap, reminds us again of the importance of a clear and agreed terminology. The differences between Agerholm's approach to classification and that of the WHO (described in the previous Chapter) stem from the different models of the disease process and its consequences used. This matter has already been discussed in Chapter Three, but it is so fundamental to an evaluation of competing classifications that it is mentioned again here. No compromise approach between Agerholm's and the WHO model seems possible. In the WHO model, handicap is conceived primarily in social terms as disadvantage consequent on the interaction between what Agerholm would designate as intrinsic and extrinsic handicaps - the intrinsic handicaps in terms of the WHO model being the individual's impairments and disabilities. By contrast, Agerholm's 'intrinsic handicaps' are to to be identified with impairments and disabilities. Hence, for example the 'handicap' of a particular man who has become blind at, say, the age of 30, would for Agerholm probably reside mainly in the blindness itself as this is the 'intrinsic' handicap. In the WHO scheme it would probably lie in the disadvantage that the man could no longer follow the employment for which he had been trained and to which he had become accustomed. The WHO classification at the level of handicap when applied to this man would seem, therefore, potentially well-adapted to focus on the purpose of any necessary retraining, while at the level of disability it would focus on the kind of retraining he needed. On the other hand, Agerholm's classification does not so easily move in this way from a medical to a social perspective. Rather, in focussing in the man's blindness as his intrinsic handicap, it appears to concentrate primarily on the need for treatment or alleviation of the basic handicapping condition if this is possible. An approach of this kind is obviously helpful, but it could also mean that the very idiosyncratic social and emotional effects which

blindness can have on a person's social and family life and on his personality, factors which both health and social services need to take account of, are less well-catered for than they are by the WHO classification of handicaps. Similarly, the definition of handicap as disadvantage' appears to lack the flexibility necessary for those services which are designed to meet short-term needs and which have succeeded in their purpose when they are no longer required.

In terms of the actual classification, discounting the deficiences of the basic model, criticism seems much less called for and Agerholm's own experience with a wide range of 'handicaps' and 'handicapped' persons counts in its favour. The classification is relatively brief and therefore looks sensible to medically unsophisticated users, particularly tthe disabled themselves, who are not concerned with minor discrepancies in exclusiveness and exhaustiveness. (The present author has had access to several 'expert' critiques of the classification which consist of little more than a listing of trivialities.) Serious criticism must concentrate first on the narrow 'medical' focus of the basic model, drawing on the general experience that schemes which are theoretically weak do not prosper in the long term and, secondly, on challenging even the possibility of its having broader usefulness without more provision being made for its modification in the light of use. The very simplicity of the scheme seems to preclude the possibility of fundamental changes of the kind undergone by the WHO system between draft and final proposals. The latter are, incidentally, obviously in considerable debt to Agerholm's ideas in that there is a distinct resemblance between the basic structure of the ICIDH classification of 'impairments' and that of Agerholm's classification of 'handicaps'.

Some American suggestions for classifying patients

Another overview of the need for a classification of disease consequences which extends the medical model of the disease process to patients' experience of impairment, disability and handicap has been provided by MacDonell (1976). He began with an historical outline of Canadian experience with the classification of hospital services and of patients undergoing treatment in them.

According to MacDonell, both hospitals and patients in Canada were, prior to about 1945, classified according to patients' ability to pay for treatment. The classification was, therefore quite simply, 'public', 'semi-public', 'semi-private' and 'private'. This classification carried with it 'the implication that the quality of the accommodation, and perhaps even the quality of the care provided in hospitals, bore some relationship to the patient's ability to pay'. With the advent of insurance schemes after the war, two new dimensions for the classification of hospitals and patients were introduced, one based on diagnosis and the other on likely duration of illness. The reason for the use of these particular dimensions was, quite simply, that insured hospital-care was at that time provided only for certain types of illness and for designated periods of time. Later, with the advent of federal and provincial insurance, the ability to pay became largely redundant as a criterion for hospital care. However, as hospital-care became more extensive and complex, new and more elaborate systems for classifying patients' needs in terms of type and extent of care were developed.

MacDonell gives a brief account of the development and value of some of these classification systems, summarising their contribution to Canadian experience thus:

> Canadian experience supports the general view that although clinical diagnosis is an essential item of information, it is of little basic value in a classification system. Particularly for long-term patients, some method of analysing their needs is necessary, and most systems of classification include assessments of nursing care requirements, assessment of physical functioning, and an inventory of psycho-social assets and liabilities .... To be effective and consistent, any classification system must be based on an interpretation of patient needs and be conceived for as an instrument for planning and evaluating the care of the patient, and not as an administrative device for determining fiscal responsibility.

MacDonell, therefore, provides some idea of the end-result of a good modern classification for patient-care - assessment of required care, physical functioning, psycho-social assets and liabilities and so forth. It is no longer sufficient to provide only a statement of clinical diagnosis; other kinds of information suitable for nurses, paramedical staff, social workers, ancillary helpers, and administrators must all be included.

Multi-purpose classifications

Sartorius (1976), another American researcher, would agree with MacDonell's view of the kind of classification needed. During the course of a discussion of the ICD he suggested that the 'ideal' classification system for solving the problems of patients in hospital care which would also meet the requirements of workers with these patients would have the following characteristics:

i. it would include characteristics of the processes of care as well as of the characteristics of disease

ii. it must be a classification of individuals rather than of disease

iii. it would link together the outcome of the disease with its characteristics and so reflect change

iv. it must be suitable for use by health-care workers who are not physicians, because these workers often play a decisive role in long-term care

v. it should be stated in operational terms so that tests of validity and reliability can be carried out. (wording slightly modified).

One classification which, it might be claimed, meets these requirements is the 'Patient Classification for Long-Term Care' developed by four groups of researchers in the United States in response to the passage of legislation calling for the development and evaluation of alternative methods of caring for chronically ill and elderly persons (Jones, 1973; Densen et al., 1976). Within their discussion of the Classification, Densen et al., produced another list of the characteristics of an effective classification for long-term care. This list has obvious similarities of emphasis, but also at least one interesting difference, (see i in both lists) with Sartorius's criteria:

i. the classification must be 'patient-oriented' - i.e. the focus must be on the patient, not on his setting or the service he is receiving.

ii. the descriptors must be multi-dimensional - medical diagnosis is insufficient to determine the care a patient should receive.

iii. the descriptors should be presented in objective rather than subjective or interpretative terms.

iv. the descriptors must be relevant to the purposes for which the classification is intended - i.e. as a record of the progress and outcome of the care which is given to patients.

v. the classification must be flexible - it must help in making decisions about the services and the care required by patients and in supplying information to health departments and epidemiologists.

(op, cit., wording slightly amended)

Densen et al. also described the main ways in which the Classification has so far been used. These are stated to be

i. monitoring the quality of care given to patients

ii. policy-making for long-term care

iii. research into various aspects of care

iv. training students and nursing and medical schools in techniques of assessment.

Hitherto, the classification has mainly been applied to adults in institutional settings, but Densen et al. suggest that a further fruitful area for its application would be in the assessment of children with chronic disease and disablement since there are large numbers of such children in need of long-term care.

The system proposed by Densen et al. is by no means unique in the United States but, because of the thoroughness of its preparation, it is a model for the design of classification systems on which instruments for the assessment of patients suffering long-term disablement could be based. However, a note of caution seems in place, though probably it is hardly

needed on this side of the Atlantic. The administration of the classification and the compiling of the data for each patient would appear to take hours if not days. Even if the records were held in a computerized system which provided for automatic transfer of data already known, a total change in record-collecting and keeping practices would seem to be required. A good deal more monitoring of experiments with this and similar systems would need to take place before the pay-off would appear to justify the expenditure of money and effort needed to implement this kind of system. Perhaps the more modest processes and systems recommended in books such as that edited by Benjamin (1977) is as much as can be attempted at present. Even more modest but apparently very necessary is a proposal of Williams (1978). He has suggested the development of a limited common core of some fifty items of information collected in a disciplined way according to standard definitions and conventions, concerning four or five dimensions of disability and some essential background data (age, sex, marital status etc). This information would be collected from all respondents in research projects, though individual researchers would add whatever other information they wished for their own particular purpose. Williams suggests that in this way a considerable data bank on the prevalence of impairment/disability/hanidcap and the impact of different policies on them. He also feels that it would 'facilitate more systematic comparison of otherwise disparate incommensurable surveys done sporadically, and sometimes rather eccentrically, by researchers and field authorities'.

Computerized numerical classification techniques

Reference was made in Chapter Five to the use of 'objective' methods of classification in which characteristics of the entities to be classified are coded numerically, after which the entities in coded form are assigned to classes automatically by computer. Classes are formed, therefore, on the basis of 'clustering' entities having a large proportion of coded characteristics in common. A few examples of the use of this procedure of cluster analysis familiar to the present author will now be briefly described.

The first example represents a straightforward use of one particular technique of cluster analysis in a field with some relevance to health-care. An attempt was made to classify the local authorities responsible for personal social services by a member of the Statistics and Research Division of the Department of Health and Social Security (Imber, 1970a) The aim was to produce a kind of 'family tree' for the authorities showing which of them were most related to each other in terms of specified characteristics. In a rather pedestrian sense, the results appear to have 'face' validity since, in general they accord with what might be expected. Contiguous authorities which are both broadly rural or urban are shown as being very similar: examples are: Berkshire and Buckinghamshire, Avon and Gloucestershire, Derby and Leicestershire, Sefton and Wirral, Wakefield and Barnsley. It seems clear that this kind of analysis is potentially valuable for reducing a large quantity of data to a comprehensible format so that authorities can have reasonable confidence that they are acting sensibly when they draw on one another's experience before decisions are made.

More directly relevant to health-care are certain classificatory analyses which have been undertaken by the Local Government Operational Research Unit (LGORU). One of these, which used a different clustering technique from that used in the previously mentioned study, was an exploratory study aiming to determine whether it was possible to identify about 20 or 30 people, each representing a group or cluster of people, to stand as proxy for a population of elderly people in Sheffield (Brotherton at al., 1971). This study was thought to be successful enough to justify two further studies using a similar technique in which the Unit co-operated with the Local Authority Social Service Unit at Birmingham (Davis, 1974). All these studies were designed to serve as a basis for planning a local authority programme for the identification and assessment of disabled people so that their needs could be met over a number of years. Unfortunately, as is the way with so many short-term experiments of this kind, no thorough systematic evaluation seems to have been planned and reported. However, as part of a programme of inter-related studies to compare the applicability of different techniques of cluster analysis to health and social service data, Jones (1977a, 1978b) has re-analysed the Birmingham data. In some of this work he used the same technique of cluster analysis as that used by LGORU but on different sub-samples of the data. After comparing the results of using the technique on the sub-samples, Jones concluded that the clusters formed by the methods were not very consistent since only three types of typical representatives were common to each solution. However, it turned out that these three representatives stood as proxy for the largest clusters so that about 40 per cent of each sub-sample had typical representatives in common.

Jones and his colleagues have continued this work, using data provided by the Health Service Research Unit (HSRU) and the Personal Social Services Research Units (PSSRU) at the University of Kent. The studies using the HSRU data applied two different techniques of cluster analysis to information drawn from a survey of disabled people living in Paddock Wood, Kent (Jones, 1977b, 1978c; Warren, 1976). The studies using PSSRU data concern the elderly and have recently been reported (Jolliffe et al., 1980 a., b.). Jones considers that the approach has considerable potential for economically identifying and estimating the sizes of groups of people with distinct needs, so that a rapid and reasonably accurate costing of services can ensue.

In general, Jones's results to date suggest that certain techniques of cluster analysis can give useful and valid information to planners and administrators provided that the studies are carefully planned and a statement of hypotheses to be tested is drawn up. If this is done the danger of post-hoc reasoning and opportunistic justifying of results is minimized. In particular, close consideration should be given to the quality and relevance of the data to the actual problem to be solved and the use to which the results are to be put. Too often the necessary preliminary conceptual analysis of problems and situations takes second place to the numerical analysis of data.

CHAPTER EIGHT

SOME BASIC PRINCIPLES RELEVANT TO THE MEASUREMENT OF HEALTH AND DISABILITY CONCEPTS

Measurement

Until quite recently in Britain, little attempt was made to use the sophisticated ideas about measurement, commonplace in the more empirical branches of psychological and sociological investigation, for the measurement of health and disability concepts. However, the work done in the last twelve years or so, particularly by researchers such as Jefferys et al. (1969), Wright (1974), Williams et al. (1974), Garrad (1974), Benjamin (1976) and several others, shows that a change is gradually taking place. In addition, the evaluation and monitoring of health care by an application of work first done in the United States on the measurement both of health states and of activities of daily living is increasing rapidly.

Some examples of this work will be discussed at appropriate points in subsequent chapters. The primary aim of this chapter is to present, in as simple a form as possible, an approach to some basic ideas of measurement. This should enable those who wish to do so to understand the main problems which arise when measures for assessing concepts such as 'health', 'disability' and 'handicap' are constructed and used.

Like classification, measurement is a word which can describe a variety of processes. There will probably be few concerned with measurement in any context who would dissent entirely from the view expressed by Jones (1971):

> 'There is no right definition /of measurement/. As with definitions of other concepts, one simply is faced with a need for establishing a semantic convention for purposes of communication' (op.cit., p.336).

At the practical level, therefore, measurement is usually best defined 'operationally'; ie the activities or operations which constitute measurement in the particular context in which the measurement is to take place are precisely specified (supra p.11). However, at the theoretical level, some fairly settled approaches to basic ideas exist. That developed by Stevens in a succession of papers, the first one being written in 1951, is briefly described below.

Stevens (1951)* defined measurement as 'the assignment of numerals to objects or events according to rules' (op. cit., p.1). It is also illuminating to turn this definition round: 'When numbers are assigned to objects or events according to rules, measurement is taking place'. The key to good measurement is, therefore, good rules. This approach to measurement settles controversies that might arise as to whether particular entities are measureable. Providing rules for assigning numbers can be devised, some kind of measurement of the entities is, in principle, possible, though consistent rules are obviously best.

The wide utility of Stevens's definition can be shown by applying it to diseases and their consequences. If measurement can consist merely of applying numbers to entities in some consistent, rule-bound way, this is exactly what is done when, for instance, the presence of a disease having been diagnosed, the disease is put into its place within the ICD. It is the same with the consequences of disease when these are assigned to categories within the new ICIDH. Classification in the sense of assignment to categories is a process of measurement.

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*A readily accessible source in which Stevens had summarized his approach is Stevens SS (1974) 'Measurement', in Maranell G M (Editor) Scaling: a Sourcebook for Behavioural Scientists, Chicago: Aldine Publishing Company.

Levels of measurement

Within the definition of measurement he proposed, Stevens found it useful to distinguish four major types or 'levels' of measurement. In order of increasing precision these are (i) nominal (ii) ordinal (iii) interval (iv) ratio. Each level has the properties of the preceding level together with a new defining property. Nominal measurement can be exemplified by the assignment of entities to categories in systematic classifications such as the ICD and the ICIDH. In classifications of this kind the numbers assigned to the classes are not much more than convenient labels, though the articulation customary makes the classification systematic.

In the simplest form of the next, ordinal, level of measurement the entities being measured can be 'rank-ordered' in terms of definable characteristics, properties or attributes. At this level of measurement numbers are assigned to entities according to their rank. Thus an entity to which the number '3' is assigned will, in some sense, be always consistently higher or lower in rank than an entity to which the number '2' has been assigned.

The next higher level is interval measurement. This is often usefully referred to as equal-interval measurement because numerically equal differences also represent equal differences in the entities or attributes being measured. Finally, at the highest level of all there is ratio measurement. This has the properties of interval measurement together with the extra property that the numbers assigned stand for actual quantities of the entity or attribute being measured. In particular, the number zero is only assigned when none of the entity or property is present.

These four basic levels of measurement can be distinguished from one another not only by the rules for ascribing numerals as outlined above, but also by the statistical procedures that can be applied to the data obtained by applying them. If we think in these terms, a simple alternative classification of levels of measurement is sometimes more useful. Under this system, nominal data, ie data produced by nominal measurement, are described as categoric, while ordinal, interval or ratio data are described as continuous. This permits the description of a useful hybrid category of dichotomous or binary data to describe data produced by measurement, usually at the ordinal level, which assigns entities to one of two response-categories only (eg yes/no). Special statistical procedures are available for analysing binary data, the data being treated as categoric or (more usually) as continuous as appropriate (Youngman, 1979).

The level of measurement at which one works depends mainly on the nature of the entities, concepts or attributes being measured. As has been indicated, qualitative attributes such as a person's name and certainly his diseases, can be assigned to classes and therefore 'measured' at the nominal level. At the other extreme, only physical entities and their abstracts, length, weight, velocity, etc., can normally be measured at the ratio level. In fact, it is sometimes suggested that in the social sciences we are seldom concerned with measurement at either this or the interval level, only with the two lowest levels. However, this is not always so and, as a later section of this chapter will show, it is sometimes sensible to proceed with the statistical analysis of data, ostensibly obtained by measuring at a low level, as if the higher 'metric' (i.e. interval or ratio) levels of measurement have been reached.

Scales and scaling

In terms of Stevens's description of levels of measurement, a scale can be defined roughly as Kerlinger (1973, p.492) has proposed: 'a set of numerals so constructed that they can be assigned by rule to those entities (individuals or behaviours) to which the scale can appropriately be applied'. In practice, however, the term 'scale' is not always confined to the set of ordered numerals, but is applied to the entire measuring instrument. Thus, when we employ a balance to measure the weight of an object, we often speak of the numerals on which the pointer indicates the weight of the object as the 'scale', but we also speak of the whole balance as 'scales'. Similarly, we sometimes refer to an instrument measuring subjects' performance or capabilities in 'activities of daily living' (ADL) as a 'scale', even though there is not always much evidence that the rule by which the numerals are applied fits typical data reasonably adequately. However, if such evidence is found, or if the scale is constructed by a recognised method so that a consistent rule applies, the term 'scale' is then, of course, wholly appropriate.

There are several systematic procedures available for the construction of scales to measure attitudes, values, etc. on the basis of people's answers to questionnaires. Oppenheim (1966) has briefly summarized and compared the well-known methods of Thurstone (Thurstone and Chave, 1929), Likert (1932) and Guttman (1950). These scaling procedures all represent advances on the simplest 'method' of all which merely assumes that a set of questions of the type 'can you feed yourself?', "can you get out of bed?' etc., forms a reasonably consistent scale; the total disability of the individuals answering the questions being measured by counting the number of negative answers they give, each question counting as one unit on the 'scale' of disability.

Thurstone's method, for instance, attempts to locate the 'items' (questions, statements, etc.) at points on a hypothetical scale with equal-appearing intervals. These provisos arise because the scale constructed is based on

psychological rather than numerical units - the opinions of 'judges' being used to construct the scale.

The rationale for Thurstone's approach is provided by results from research on perception summarised in what has become known as the 'psychophysical law': 'equal stimulus ratios produce equal perceptual ratios'. What this means in practice is that when stimuli are presented one by one to an observer, he can assign numbers to reflect his subjective impression of the intensity of those stimuli in such a way that they are consistent with the numbers assigned by other observers. This procedure has been shown to be effective with simple physical stimuli such as lengths of lines, brightness of light-sources and loudness of sounds, but there is evidence that it works also with more complex multi- dimensional stimuli. Perhaps one of the most interesting of examples of an application of this concept of psychophysical scaling appears in a study by Sellin and Wolfgang (1964). This study aimed to measure the harm done to the community by crimes committed by juveniles and achieved considerable success in showing the possibility of scaling at the ratio level the degree of delinquency exhibited in various kinds of crime. There was, for instance, general agreement among quite disparate groups of people that stealing and abandoning a car is only about one-tenths as serious as robbing a man of $5 and wounding him in the process. The assumptions behind Sellin & Wolfgang's work have been challenged (Rose, 1966), nevertheless, in the next chapter, a description is given of how the same general approach has been successfully used for constructing a health index.

Scalogram analysis

This approach to scaling has been made use of to measure disability by Williams et al. (1974). The method was devised by Guttman (1950) and can be most simply illustrated by applying it to items such as the questions in an ADL measure of the kind mentioned in the previous section. It has long been observed that, for instance, a negative answer to the question

'can you feed yourself?' will usually be accompanied by the same answer to 'can you dress yourself?', while the reverse is seldom the case. This kind of observation forms the basis for the construction of 'cumulative' scales. The working principle of this kind of scale can be made clearer by taking as an example three of these self-care questions being put to four individuals. The three questions are:

(a) can you feed yourself?
(b) can you dress yourself?
(c) can you get out of bed?

Person 1, who answers 'no' to (a) will usually also answer 'no' to (b) and (c). Person 2, who answers 'yes' to (a) but 'no' to (b) will usually also answer no to (c). Person 3 answers 'yes' to (a) and (b) but no to (c), while person 4 answers 'yes' to all three questions. These responses can be summarised in a table as follows:

	Question			
	(a)	(b)	(c)	total 'no's = disability score
Person 1	no	no	no	3
2	yes	no	no	2
3	yes	yes	no	1
4	yes	yes	yes	0

When the responses are set out in this way, the relationship between the pattern of the responses and the total disability scores becomes clear: if we know a person's total score we can predict the pattern of his scores.

When scalogram analysis is applied to real people with real disabilities in real contexts, there is always a certain number of people whose total scores do not exhibit the expected pattern - so called 'non-scale types'. In typical samples of disabled people it seems that about one-third fall into this category.

Extensions of scalogram analysis have been developed by Guttman and his colleagues to analyse these non-scale types. One such is 'partial order' scalogram analysis (Shye, 1978) which includes a rapid method of identifying them for separate analysis. Canter and Barnitt (1980) have used the method to look at 'non-scale types' in homes for the physically handicapped in work approaching completion.

'Rasch' measurement

Some of the analytical problems raised by non-scale types also seem to have been solved, though only for measures containing dichotomous items, by a method of analysis first suggested by Rasch (1960) and since developed by Wright and his colleagues (eg Wright and Stone, 1979). In this method the responses of individuals to items in measures is conceived of as an interaction between the 'ability' (or disability) of the persons and the 'difficulty' of the items. The distinctive contribution of this approach is that the mathematical 'model' employed to relate ability and difficulty enables the probability that a person with a certain ability can respond successfully to an item of certain difficulty to be calculated. Both non-scale persons and non-scale items can thus be identified for closer examination.

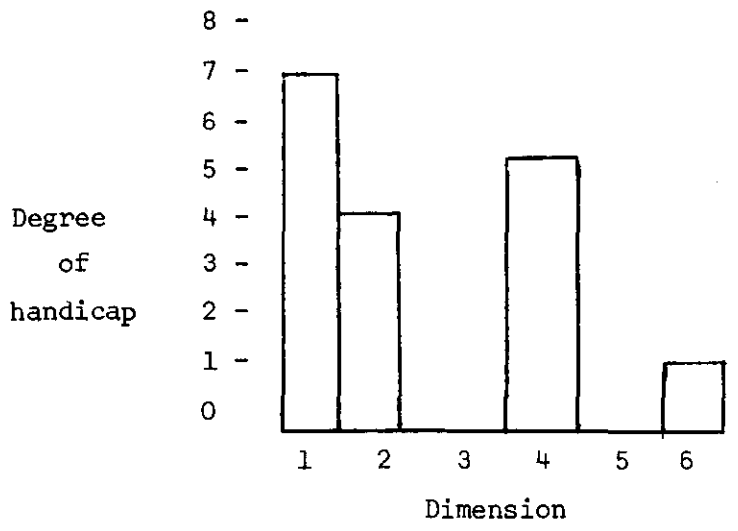
Profile measurement

Generally speaking, as Guttman observed, questions or items which do not fit into a cumulative scale are measuring, at least in part, some other entity or attribute from that which the main body of items is measuring. A fully cumulative scale can therefore be treated as if it were 'undimensional' - ie measuring one aspect or attribute of experience and one only. Unfortunately, in most practical contexts of interest to health professionals, measurement is more likely to be concerned with complex 'multidimensional' entities and attributes. The usual way of meeting this situation is to identify the dimensions and to measure each separately.

The dimensions of 'handicap' proposed in the ICIDH provide a good example of how dimensions can be identified by an application of fundamental theory. The theory of survival roles (Maslow, 1954) suggests that 'handicap', in the sense of disadvantage resulting from impairment or disability, requires at least six dimensions to characterise it completely. Measurement then proceeds at the ordinal level on all these dimensions simultaneously but separately, so that handicap is assessed from several points of view at the same time. The best way of preserving the details of the measurements made is to present them in terms of a profile: a set of results based on different scales in which the scales are adjusted to use the same unit of measurement. An individual's scores on the series of handicap dimensions determined in the way suggested in the ICIDH would clearly constitute such a profile.

The most accurate way of representing an ICIDH profile of handicap is by means of a six-digit number with each digit corresponding to the specified degree of handicap in that dimension. However, the representation by means of histograms such as those shown in Figure 8.1 is more intuitively appealing than the numerical alternative: 740501.

Figure 8.1 An example of an ICIDH handicap 'profile' in histogram form



The main problem with the measurement of concepts in terms of a profile of scores is the possibility that the chosen dimensions on which measurement takes

place are not really conceptually independent on one another. This is important as independence of dimensions maximizes the quantity of information supplied. Conversely, correlated dimensions reduce the quantity of information and may mislead because repetition may appear to the unwary as new information. Without empirical testing to prove the matter one way or the other it would seem not unlikely that, for instance, there might often be significant overlap in the form of positively correlated scores on the 'occupation' and 'economic self sufficiency' dimensions of handicap in the ICIDH.

Profiles constructed on the basis of clinical examination have been found very useful for recording estimates of measurements of 'qualities' which might be affected by disease, impairment or disability among members of the British armed services. (Fletcher, 1949). In fact, they were introduced in 1948 (War Office, 1947) and are still in use today with only slight modifications. The method used is usually referred to as the 'PULHEEMS' system because it reports seven different qualities designated as follows:

P = Physical Capacity

U = Upper limbs

L = Locomotion

H = Hearing (acuity)

EE = Eyesight (visual acuity)

M = Mental Capacity

S = Stability

Warren (1956 has described a study involving 600 men and 400 women in civilian life to whom the PULHEEMS system was applied. He concluded that a modified version of the system would be valuable for the purpose of analysing statistically the results of routine medical examinations on civilian populations. This proposed use of the PULHEEMS system for adults has been followed by a trial of the PULHESTIB system based on similar principles but applied to children (Holt, 1957). A further development for children is the PULTIBEC system described by Linden (1963) and since used in research by Anderson (1973).

Finally, the PULSES profile devised by Moskowitz and McCann (1957) has been adapted by Granger and his colleagues in current work aiming to apply and evaluate systems for assessing the outcome of rehabilitation (Granger and Greer. 1976; Granger et al, 1979).

Unidimensional Health and disability indices

Most concepts of interest to health professionals refer to latent entities, concepts and properties which are, like handicap, multi-dimensional. Disability as defined in the new WHO classification, as well as 'health' itself, are other examples of obviously multi-dimensional concepts. If an entity is multi-dimensional it can only be completely described empirically if measurement on all dimensions relevant to the context has taken place. The obvious product of such measurement is, as the previous section suggests, a profile of separate scores.

In many practical situations however, a profile is inconvenient for making straightforward comparisons between individuals. Those who might wish to distribute services to out-patients or patients in the community on the basis of some measure of total disability or handicap would find several scores on separate dimensions of a profile quite unsuitable for decision-making. The answer is to find a method for combining the scores. One way of doing this would be merely to add them together, but this is obviously a very dubious procedure as there is no sense in simply summing measurements which belong to different dimensions of experience. For instance, even if they have been measured on a similar scale, '(lack of) mobility' cannot reasonably be added to '(lack of) economic self-sufficiency'.

There are, in fact, other ways of proceeding. One is to find some principle derived from theory or from observation which will justify weighting the scores obtained on the chosen indicators or dimensions so that they can be combined

simply by summing the weighted scores. An example of this procedure which will be referred to in Chapter Ten is the method of weighting scores used in the OPCS survey of 1968-9 (Harris et al., 1971). Another method is to devise and use a formula which will combine scores gained on different dimensions in a more sophisticated fashion. Formulae of this kind can become very sophisticated indeed, as exemplified by many of the 'Health Mathematical Models' constructed in the USA in the 1960's. The symposia resulting in the publication 'Health Status Indexes and a complete issue of the journal 'Health Services Research' discussed a number of these. (Berg (ed) 1973, 1976).

Bice (1976) has criticized some of the early models containing complex formulae for combining indicators or dimensions, especially when these are based on a priori principles. He describes them as 'mathematically ingenious, albeit conceptually naive' because they represent 'the apparent ascendance of conceptual expansiveness and methodological rigour over practical utility'. Instead, he expresses a preference for indicators and indices which are mainly judged by their post-facto practical usefulness to decision-makers. Such indices, he remarks, will be 'calibrated in terms of socially and politically useful units'.

Bice's approach is therefore pragmatic. It can be exemplified in terms of what appears to be a fairly standard method of index construction described by Mayntz et al., (1978, p43ff). In this method, multi-dimensional concepts are considered in terms of a 'multi-dimensional property space' with as many axes in 'space' as there are dimensions in the concept (Barton, 1955). Scores are then assigned to certain points in the space representing <u>combinations</u> of values on the dimensions. This assignment of scores is usually made on the basis of common sense, theoretical principles, empirical evidence or all three. Examples are given in the section on Health Indices in the next chapter.

When this method of index construction is used, the procedure explicity involves some kind of 'trading-off' of component indicators or dimensions so that an overall score can be assigned to several indicators or dimensions considered as a whole. Hence an index can be defined as 'a single measure on which combinations of attributes (dimensions, indicators) can be located'.

Raising the level of measurement

It is generally considered best to work at as high a level of measurement as possible, if only because the statistical techniques that can be applied to the data obtained as a result of measurement give more precise information when a high level of measurement has been employed. Part of the appeal of some of the formalised methods available for constructing scales discussed briefly in earlier sections of this chapter lies in the possibility that the level of measurement has been raised by their use, with the consequence that more information can be gleaned by subsequent analysis of the data produced.

These methods often employ an explicit 'scaling model', ie a mathematical expression relating the expected behaviour of the items to that of the persons responding to them in such a way that metric measurement would be applicable. The Rasch mathematical model mentioned on p.99 is such a scaling model. If this model can be shown to express the way in which disabled persons respond to items in disability measures reasonably well, then it is possible to apply to the data those methods of statistical analysis which have been worked out by statisticians and researchers such as Wright and Stone (1979).

Until the properties of the concept or relationship being measured have been thoroughly explored and an adequate model developed, an approach is often adopted in which the data produced by measurement are treated as if they obeyed a simple 'linear' model. Such a model is assumed, for instance, in the simplest method of measuring 'self-care' disability by means of an

'activities of daily living' (ADL) instrument in which positive score on the individual items are added together to give a total score. Under this model each individual item in the ADL instrument is assumed to make an equal contribution to the total concept of disability measured by the whole instrument so that the overall degree of disability is measured simply by counting the number of items of self-care with which the respondents have difficulty. If the assumption on which the model is based is reasonable, the instrument will be capable of measuring at the interval level since, when each item contributes equally, the difference between a score of 6 and one of 4 on a scale of items serving as indicators of equal quantities of disability will always be the same as the difference between a score of 5 and one of 3 or between a score of 4 and one of 2. Also, if we are willing to make the assumption that '0' (zero) disabilities really means no disabilities at all, then we can also assume that we can treat the data obtained as if they had been obtained by ratio measurement.

In the hands of experienced researchers who are aware of the assumptions being made, who have a 'feel' for the data produced by their instruments and who have sufficient resources to undertake proper validation procedures, the approach outlined above, in which interval measures are assumed to provide metric data, is often justified. Unfortunately, researchers are not always in this position and, in consequence, they sometimes apply inappropriate statistical tests and subsequently claim too much for their data.

For experienced workers the following statement by Guilford (1969) suggests the benefits to be obtained and the perils to be faced by assuming metric properties in the data produced by measures which strictly only justify an assumption that ordinal measurement has taken place:

> '... experimental data often approach the condition of equal units sufficiently well that there is tolerable error in applying the various statistics that call for them. This is one of those occasions for making use of approximations, even gross

> ones, in order that a/researcher/ may extract most information from his data. This is often justified on the basis of evidence of the internal consistency of the findings and the validity of the outcomes. This does not excuse the investigator, however, from being on the alert for intolerable approximations and for results and conclusions that are, essentially a function of his faulty application of statistics. (Op. cit., pp. 15, cited by Kerlinger, 1973).

Reliability and validity

When the measurement of degree of health or disability takes place, the quality of the data obtained can be said to depend mainly on:

i. the 'consistency', or 'accuracy' of the methods or instruments used to measure the entities being measured;

ii. the conceptual 'fit' between the methods or instruments used and the entities being measured.

These two influences on the data relate respectively to what is usually termed the 'reliability' and the 'validity' of the measurement process. Hence these attributes of measures are invariably considered in studies describing their development. The paper of Jefferys et al. (1969), which describes the development of measures of physical impairment and their subsequent validation in some detail, and a more recent paper by Deniston and Jette (1980), in which a 'functional status' instrument is validated are both good examples of such studies.

The broad theory of reliability and validity is discussed in all standard text-books which include chapters on measurement and the Professional Affairs Board of the British Psychological Society (BPS) has recently issued 'technical recommendations for psychological tests' which make useful distinction between types of reliability coefficient and ways of showing validity (BPS, 1980).

Usually reliability is treated with only minor variants of approach, hence what is written in the next section is probably a fairly standard brief treatment. Validity is a more difficult subject and the frameworks of definitions and the contexts within which it is described can vary considerably. In

the brief treatment of both concepts given in the next two sections the theoretical approaches of Kerlinger (1973, Ch.27), and of Mayntz et al., (1976, Ch. 2) are most often used. A similar treatment is provided by Carter et al. (1976) in the context of a discussion of the validation of 'The Sickness Impact Profile'.

Reliability

The qualitative idea of reliability can be expressed through the various near-synonyms of the term - consistency, stability, dependability, reproducibility, repeatability, predictability: an instrument is reliable when the data resulting from measurement with the same instrument on another occasion by someone else is consistent, etc. Often, in fact, it is better to use one of these near-synonyms because of their greater precision in a particular context. For example, in epidemiological work it is usually best to think in terms of 'repeatability' (Rose and Barker, 1979).

A quantitative approach to reliability can start with the premise that all 'scores' obtained by using a measurement method of any kind are scattered randomly about the 'true' score and are therefore 'inaccurate'. Sources of random error may lie in the measure itself, the persons gathering the data and the subjects who provide the data. Whem empirical data are gathered by means of a measure of scale, items or questions may be ambiguous, researchers may be careless, subjects may misunderstand items or be affected by extraneous factors such as excessive heat or cold, poor lighting conditions, accidental interruptions, etc. In particular, people with disabilities who are answering a questionnaire may be physically uncomfortable or emotionally involved. A useful brief summary of the sources of unreliability in the three main methods - clinical assessments, objective measures or self-report measures - used to measure disability is that of Garrad (1974). Her comments on the subject are summarised at the beginning of the next chapter.

For an objective measure consisting of more than about ten items, reliability, repeatability, etc., are usually determined by using a standard formula to calculate the average inter-correlation of random sub-sets of the items in the measure. The coefficient obtained estimates the lower limit of the 'internal consistency' of the scale. Other methods of obtaining quantitative measures of reliability have a more concrete meaning. The 'test retest' method, which consists essentially of applying the assessment device on a second occasion to an identical group of subjects under identical conditions, is a measure of repeatability. Mayntz et al., (1976, p. 65-6) briefly describe the various methods available for determining reliability and summarize their advantages and disadvantages. In any case, it is important that the type of 'reliability' coefficient actually determined should be reported, if only by indicating the manner of its determination (BPS, 1980).

Validity

Kerlinger (op. cit., p.456) states that 'the subject of validity is complex, controversial, and peculiarly important in behavioural research'. Bulmer (1977) explains why this should be so, by emphasising the inadequacy of techniques which are merely reliable:

> 'Reliability alone is not sufficient. No matter how good a result is achieved in terms of consistency this does not affect whether a technique taps the theoretical dimension specified in the problem. The validity of knowledge produced by different means - the extent to which empirical research yields knowledge about the construct it purposes to depict - is less easily determined ...' (op. cit., p.30).

Kerlinger emphasises the positive importance of validity by describing how validation procedures might explore the nature of the links between concepts, measuring instruments and the procedures themselves. He suggests that validity problems arise mainly at two points in the research process. First, there is the question of whether the observations used to define the concept and which are also used as indicators of the intended reality do actually reflect this reality. Secondly, the question of the 'operationalization' of the concept - the specification of what is to be measured, when,

and how - which is also sometimes difficult to answer satisfactorily. Fortunately, during the straightforward measurement of disease consequences the first problem should not arise in any acute form. Because impairment, disability and handicap have been clearly defined in terms which correspond with experience (as in the ICIDH), it seems likely that valid indicators are already available. The second problem, however, arises afresh and quite specifically for each research tool and for each method of data collection used.

In its simplest terms, this second problem is epitomised by two apparently straightforward questions which can be put to any instrument or method: 'Does it make sense?' and 'Does it work?'. Together they add up to the more usual way of putting the validity problem within measurement: 'Does the measuring instrument (scale) measure what we want to measure?'. Mayntz et al. (op. cit., p.65) briefly describe four methods for answering this question and therefore for establishing validity:

i. validation by experts
ii. validation by known groups
iii. predictive validation
iv. constructive validation

In Kerlinger's terms (op. cit., p.457 ff) (i) corresponds to 'face' and 'content' validation, which are both basically matters of judgement, (ii) and (iii) to 'criterion-related' validation, and (iv) to 'construct' (the more usual term) validation. Kerlinger considers that construct validation is of the essence of modern approaches to measurement since it tests the effectiveness not merely of the measure and the indicators or items in it, but of the whole theoretical system within which the measure is embedded. Hence it contrasts strongly with purely empirical approaches which define the validity of a measure mainly by its success in predicting a criterion. For instance, someone using an empirical approach to validation might argue that a particular measure of disability was valid (i) if it efficiently

distinguished individuals who were very disabled from those who were not and (ii) the distinctions made agreed with those made by doctors experienced in rehabilitation work. However, an approach to disability measurement, such as that adopted by Williams (1979), in which a theory of disability is described and in which measurement assumptions about cumulative scales are integrated with the theory, would demand measuring instruments which so depended on the theory that their effective validation would necessarily be by means of construct validation in which both instruments and theory would be examined together. In general, however, the measurement of disability and similar concepts is only just beginning to reach this level of sophistication so that empirical methods of measurement and, therefore, the straightfoward 'concrete' approaches to validation listed above under (i)-(iii) are usually deemed sufficient.

Good examples of the power of the concept of validity and the way in which validation is increasingly being approached in empirical research is provided by Deniston and Jette's paper (1980) mentioned earlier in this chapter and by Maclean and Genn's report on the methodology of a survey designed to identify people whose activities or earnings had been limited as a result of illness, injury or disability (Maclean and Genn, 1979, Chapter Three). The validation of the 'network of definitions' used in Maclean and Genn's study is described under the heading of 'construct' validity; the validation of the items in the questionnaire used is described under the heading of 'content' validity; while evidence for validity from comparisons between the data derived from the questionnaire and these from other sources is discussed under the heading of 'concurrent' validity. Further reference will be made to this aspect of Maclean and Genn's work in Chapter Ten of this study.

CHAPTER NINE

THE USE OF OBJECTIVE MEASURES FOR ASSESSING HEALTH STATUS

Using objective measures

As discussion in the previous chapter has indicated any estimate of degree of disability is likely to be unreliable to some degree and for various reasons. Thus Garrad (1974) was able to draw on the work of Kelman and Willner (1962) to make the point that clinical assessments of degree of disability made by members of different professional groups seldom agree because they inevitably use different criteria for assessing performance. (She does not comment, however, on the differences in the assessments made by members of the same professional group.) Garrad also remarked on the problems which arise from unreliability in self-reports of disability. Consequently, she commends particularly the measurement of disability by using standard measures of performance (tests) conducted by an observer trained in their administration. Unreliability is reduced when disability is assessed by instruments of this kind even though a subject's performance will still tend to vary with different test administrators or in different environments (Wright, 1974). Nevertheless, they can, perhaps, claim to be reasonably 'objective' in that they largely remove the more obvious biases stemming from the circumstances surrounding the test administration. In consequence, the use of these relatively 'objective' measures of disability has probably increased in recent years. The next two chapters of this study will therefore extend the discussion of this kind of measure. Readers may already have noted this emphasis as beginning in the previous chapter.

ADL indices (indexes)

Many of the measures used for assessing individuals tkae the form of 'ADL' (Activities of Daily Living) measures of indices. These are perhaps the most straightforward form of objectives measure used in assessing disability. They are used particularly in rehabilitative medicine by occupational therapists

and others to estimate the progress of patients during treatment or to determine the outcome of treatment. Several useful reviews and classifications of ADL measures have been produced. One of the best is that of Bruett and Overs (1969). They examined 12 ADL scales, classifying them into three types mainly distinguished by their purpose and manner of scoring. Table 9.2, which is based on one of Bruett and Over's tables, shows this simple classification.

TABLE 9.2 THREE TYPES OF ADL MEASURES

Type	Purpose	Scoring
1	To inventory severity of disability in populations and to measure effectiveness of overall treatment.	Additive scale giving total scores.
2	To construct ability profiles that match activities patient can perform.	Non-totalled, non-averaged profiles.
3	To assist in prescribing treatment and to measure patient's success in attaining goals.	Long. Not usually additive. As many items as necessary to record all programmed activities.

Check-list Measures

Bruett and Overs' 'Type 2' measures incorporating profiles have been considered in sufficient detail in the previous chapter of the present study. Their 'Type 3' measures include the commonly-used 'check-list' type of ADL measures which operate at the nominal level. This type of measure is discussed by Oppenheim (1966). He suggests that they are at their best when they are constructed to test specific hypotheses rather than as exploratory tools. Inevitably, health workers will eant to use them exploratively. In this case, Oppenheim's warnings are apposite.

'... /check-lists/ operate at the conscious and overt level and run the risk that the respondent ... will try to 'help' by making the results come out the way he thinks they should'.

'... we must maintain a critical attitude and ask ourselves what this set of questions is trying to achieve, and how the results will be used. Many such devices have been hurriedly put together and suffer from lack of pilot work, poor coverage, and doubtful validity'. (op. cit., p. 2).

An example of a check-list measure for which the constructors have deliberately tried to avoid the worst faults mentioned by Oppenheim is the 'second' ADL index devised by workers at the Northwick Park Hospital (Benjamin, 1976). This was constructed as part of an attempt by the British Association of Occupational Therapists (BAOT) to produce a method of recording ADL assessments which would be acceptable in a wide variety of settings. The index was aimed at assessing many areas of disability, such as the use of public transport, hobbies, social contracts and interest. It was also designed to be used with patients in their own homes so that specific disabilities and handicaps can be more easily inferred (Goble, 1976). For various reasons, spelled out by Jay (1976), neither this nor the 'first' index (discussed later) were found acceptable. Hence the Northwick Park Indices have turned out to be examples of good practice rather than 'BAOT recommended' indices.

Categorization and dimensions in ADL indices

Goble's insight into the best use of a check-list ADL measure has been taken up by Smith and her colleagues in Edinburgh (Smith et al., 1977). More recently Smith (1980) has described the principles governing the design and context of an index suitable for making a reliable 'home' assessment while the patient is still undergoing treatment in hospital. Her conclusion is that 'a simple record designed to reflect the ability of each patient to carry out essential daily tasks in their own home would be most likely to provide a reliable method of recording useful functions'.

However, a record able to reflect and compare patients' abilities obviously requires an instrument measuring at a level higher than that nominal. In fact, Smith proposed a profile-type measure such as one would expect from an assessment with aims similar to those of a Bruett and Overs' Type 2 measure. She suggests that the profile scores should be recorded on a grid in the way shown in Table 9.3. Grids of this kind appear to provide an economical method of recording ADL assessments.

TABLE 9.3 TYPICAL ADL ASSESSMENT ON EDINBURGH SCHEME

	(Low) - Level of disability - (high)								
Activity	I	II	III	IV	V	VI	VII	Outcome	
Bed	✓							1	
Dressing		✓						2	Summary outcome
Mobility				✓				4	1245521.
Hygiene					✓			5	
Cooking					✓			5	
Feeding		✓						2	
Environ-ment	✓							1	

An unusual feature of Smith's measure is that seven categories are used within each activity. Seven is an uncommonly large number of categories and some workers have suggested that two or three are enough (Iverson, 1968; Bruett and Overs; 1969). However, provided that users of the index can cope, too many categories are better than too few as the reliability of the observations made will almost certainly be increased. The categories proposed by Smith are shown in Table 9.4.

TABLE 9.4

Categories proposed by Smith (1980)

I	Completely independent.
II	Independent using prescribed aids.
III	Requiring supervision for safety, but no physical help.
IV	Requiring light physical help from one person.
V	Heavily dependent on help from one person.
VI	Requiring help from 2 people at the same time.
VII	Completely independent.

The WHO (1980) proposed Severity of Disability scale, shown in Table 9.5 uses 6 categories and the scaling implied in the category definitions has some differences from those proposed by Smith. There is, for instance, a category between Smith's I and II in which the individual can perform the activity unaided but with difficulty. On the other hand, Smith has a category between the WHO categories 2 and 3. The relationship between the proposed scales is shown in Figure 9.6.

TABLE 9.5

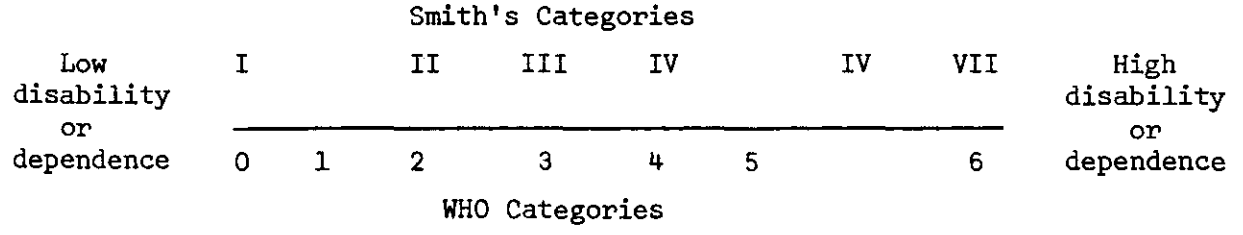
Categories proposed by the WHO classification

0	Not disabled.
1	Difficulty in performance (but no aids).
2	Aids and appliances necessary.
3	Assisted performance (a helping hand).
4	Dependent performance (completely dependent on another person).
5	Augmented inability (another person using aids).
6.	Complete inability.

Which is the better as a scale can only be determined by empirical study. The problem, as with any scale, is to estimate the location of the proposed categories as points on the line implied by the concept or variable (disability or dependence) measured by the index. Ideally, the points should be spread out along the line from low to high disability. The precise position of the points

FIGURE 9.6

Hypothetical results of using different categories to measure the score concept



on the line could be determined by one of the methods of scaling mentioned or described in the previous chapter.

Deriving Summary Scores from ADL indices

Smith (op. cit.) has also discussed the possibility of obtaining a single summary score such as Bruett and Overs suggest as being typical of their 'Type 1' ADL measures. On balance, she rejects the idea, though she does point out that the highest level of dependence recorded for any activity might be useful as a measure of overall dependence/independence level.

The 'First' Northwick Park Index (Benjamin, 1976) is an example of an ADL index which was aimed partly at supplying a single score. Another is that produced by Brocklebank and his co-workers (1978). Preliminary work for the latter measure was undertaken by Andrews (1976), who critically reviewed earlier attempts to measure disability. His starting point was that:

> 'Comparison of the findings of different research groups has been complicated by the lack of a standardized scoring system for the measurement of disability and progress'.

However, after trials of two scoring systems for an index based on that of Katz et al., (1963), he concluded that all scoring systems have the disadvantage that potentially valuable information is lost during their application. Andrews found that when 'real' data were examined the same score for two patients or even the same patient at different times often obscured large qualitative differences in the pattern of disabilities actually experienced.

Many of the problems of using ADL measures to provide summary scores were thoroughly discussed by Kelman and Willmer as long ago as 1962. At the outset of their work they noted that in their study 'the same population measured by different examiners (equally qualified) under different test conditions yielded different results'. They considered that the generality of this observation was probably the resultant of several interacting effects - that of differences in environment (inside or outside the patients' homes), that of different health workers undertaking measurement, that of different test methods and that of the normal day-to-day variability of patients. Similarly, they questioned whether the observed reductions in level of performance stemmed from deterioration resulting from disease processes, from differing expectances of performance in a different environment or from discrepancies in test performance under different testing conditions. Kelman and Willmer also examined three methods of combining the dependency-independency scores obtained on individual ADL items. Their conclusion is that a single score which is intended to summarize the totality of functions of a persons will obscure the pattern of change in each function. For all these reasons, they conclude that nearly all summary measures of outcome after rehabilitation, whether clinical or instrumental, are inevitably liable to be of doubtful reliability and validity. The present author concurs with this conclusion and has expressed his reservations about a widespread use of these measures in a recent journal article (Duckworth, 1981).

The work of Katz and his colleagues

Almost all the researchers who have designed ADL indices in recent years cite the work of Katz and his colleagues with considerable approval. Thus Benjamin (1976) comments that most British indices were declared unsuitable to serve as a basis for the envisaged BAOT-recommended indices because insufficient attention had been paid to their validation, evaluation and revision. By contrast, the various papers describing the work of Katz and his colleagues show that considerable resources were devoted over a long period of time to the development and validation of their index. For instance, more than 20 workers are listed as co-authors of the many papers describing the work done on the index over a period of more than 20 years (eg Staff of Benjamin Rose Hospital, 1958, 1959; Katz et al., 1963, 1970, 1976). Katz and Akpom (1976) provide the best summary of the index in its present state of development and the brief account which follows is mainly based on this summary.

First, Katz and his colleagues identified a set of functional activities 'hierarchically' (cumulatively) related to one another. These activities; feeding, continence, transferring from (bed), toileting, dressing and bathing, in that order, enabled individuals to be ranked on a scale by means of a single grade based on the number of areas of dependency in ADL. Then developmental studies were undertaken on samples of a wide range of chronically ill and disabled people in various settings; children and the mentally impaired were included.

Although standard methods of scalogram analysis were employed to study the functioning of the proposed scale, the form of grading actually employed was designed to reduce the number of non-scale types to a minimum. Also, the activities in the index were carefully defined so that data recorded on the standardised assessment form could be reliably converted into a grade. It is claimed that the inter-observer reliability (repeatability) of the index is high: differences between trained observers occuring only once in 20 evaluations or less.

The theory underlying the index is based on observations that the functions included in the index and their characteristic order reproduce the recognised patterns of child growth and development in present-day societies as well as the behaviour of members of primitive societies as well as the behaviour of members of primitive societies. In particular, it was observed that disabled patients recovered in three stages (a) return of independence in feeding and continence (b) recovery in transfer and toileting (c) recovery in dressing and bathing functions. This pattern, it is claimed, is similar to the progression of development of those basic functions in children. Subsequent studies of the predictive capacity of the index are reported as contributing further to the construct validation of the index and its theoretical basis.

Finally Katz and Akpom mention some of the studies in which the index has been used. One major system, the Patient Classification for long-term care (Jones, 1973), which uses the index to classify patients' long-term care, has already been referred to in this study. In Britain, Benjamin (1976), Smith (1980) and Canter and Barnitt (1980) have all acknowledged their debt to the insights provided by the many accounts of work done with and on the Katz ADL index.

Output measures

Wright (1974) has discussed many of the issues raised above in relation to ADL measures in the wider context of measures of disability and dependence serving as output measures for the evaluation of social policy and planning of services. His discussion contains a useful review of some earlier attempts to measure physical dependence in the elderly. The work of Townsend (1962), Katz et al. (1963), Wylie and White (1964), Carstairs and Morrison (1971), and Harris et al. (1971) is discussed in detail. Wright also pointed out the need to include measures of psychological and social dependency factors in a comprehensive output measure. On the whole, less work has been undertaken on

measures of this kind, through several researchers, mentioned by Wright (1974) have appreciated the need and have incorporated relevant questions or measures into their studies.

Wright also pays considerable attention to the problems of scoring composite measures, again quoting the reservations of Kelman and Willner (1962). His own solution to the problem is described in a later paper (1978) in which he rejects the idea of a scoring system and develops a four-rank ordinal system instead. The ranks in this system are labelled 'high', 'medium', 'slight' and 'low' and the various possible responses to the items in the measure are grouped into the ranks largely on common-sense principles. The system is applied to three dimensions of output: mobility, capacity for self-care and mental state; Table 9.1 describes this scheme for the 'mobility' dimension and shows how the ranking can be simplified because only eight of the possible 16 combinations of four aspects of mobility need be considered for ranking.

Wright used a cumulative technique to order the items into a scale. Provided that items are chosen with care and severely limited in number, the approach appears to give satisfactory results with some groups of elderly people. He also compares his ordinal system with a simple scoring system. He concludes that agreement between the two is good only for very dependent and independent persons. Which is the 'better' scheme is difficult to say since the two systems are not really comparable. Under the scoring system the trade-off between different dimensions is arbitrary; under the ordinal system a trade-off is not really attempted at all. So Wright ends by finding a justification for his approach within the basic problem of weighting items or dimensions as raised by Culyer (1978) in work discussed later in this chapter (p123f). Like Culyer, Wright implies that, however painstaking the empirical work of

TABLE 9.1 RANKING OF MOBILITY DEPENDENCY UNDER WRIGHT'S SCHEME

Route No	Questions: Able to get in and out of bed and/or chair	Able to negotiate a level surface	Able to climb stairs	Able to go outdoors	Rank*	Comments
1	No	No	-	-	High	
2	No	Yes	No	No	High)	Likely to apply to people able to propel a wheelchair
3	No	Yes	No	Yes	Medium)	
4	Yes	No	-	-	High	
5	Yes	Yes	No	No	Medium	
6	Yes	Yes	No	Yes	Slight	
7	Yes	Yes	Yes	No	Medium	
8	Yes	Yes	Yes	Yes	Low	

The following combinations were not considered:

Yes	No	Yes	Yes	) The inability to negotiate a level surface will make the last 2 questions redundant - see routes 4 and 1.
Yes	No	Yes	No	)
Yes	No	No	Yes	)
No	No	Yes	Yes	)
No	No	No	Yes	)
No	Yes	Yes	No	) See routes 2 and 3 - people using wheelchairs will be unable to climb stairs
No	Yes	Yes	Yes	)

Source: Wright (1978) Table 4.1.

developing scales has been undertaken, informed judgement is inevitable at some stage if the fullest possible use is to be made of them:

> 'If we are to use these measures /of dependency/ to improve the allocation of resources, then some relative valuation of various dimensions of output has to be made to make it commensurable with the costs side. We are not yet in a position to make these valuations, but we still feel that we could use the ordinal method to some advantage in the measurement of the effectiveness of services.' (Wright, 1978, p. 60).

Health status indexes

ADL and output measures as discussed so far in this chapter are particular examples of what are more generally known as health status indexes (indices) or measures. These are widely used, especially in the United States, to evaluate the effectiveness of health services provided to individuals with chronic disease or disability.

A scheme for organising and summarising the present state of knowledge regarding health status indexes has recently been suggested by Jette (1980). The scheme has four dimensions (i) conceptual focus (ii) intended function (iii) psychometric quality and (iv) technique of data collection. The first two of these dimensions are particularly important for surveying what is available. They enable a classification to be constructed in which 'general' health indexes, suitable for describing the total health of a population and based on one or two broad indicators, are distinguished from 'health evaluation indexes' suitable for evaluating the delivery of health services. Many recently designed indexes, however, can be used to serve both purposes. A reason for this is suggested by Bice (1976), whose desire for health indexes calibrated in terms of socially and politically useful units was mentioned in the previous chapter. He has argued that, until quite recently, policy makers were content with indices which combine one or two broad but measurable indicators like mortality and life expectancy. Nowadays, however, as the Introduction to the WHO Classification of Impairments, Disabilities and Handicaps (1980) points out, it has been realised that mortality rates have become much less appropriate as a health indicator. Correspondingly, morbidity rates have become much more appropriate. Unfortunately, morbidity is a much more complex concept than mortality and seems likely to require a larger number of indicators for its accurate measurement. The result is that indexes based on several indicators or dimensions are required. In consequence, whatever method is adopted for their construction and for scaling their dimensions, the procedures involved in constructing modern indexes are inevitably quite complex.

In one commonly used method for constructing health indexes, weights (scale values) are assigned to each indicator or dimension on the basis of theory or experience. Economic criteria are sometimes favoured to provide the basis for this assignment, a value being put on individuals according to their estimated life-time earnings (Rice, 1966). This approach has not generally proved satisfactory because the greater part of medical care is required for disabled and, therefore, 'unproductive' persons (Berg, 1973, p.254). Hence several alternative criteria for assigning weights to items or dimensions have been suggested. The one particularly commended by Rice (op. cit.) consists of scaling self-reported illnesses in terms of the types and amounts of health services that would be required to care for those who have them.

Values in health indexes

A discussion of the principles behind the development and use of health indexes by Culyer (1978) has also drawn attention to the problem of assigning weights to indicators during their construction. Culyer suggested that whenever an index is constructed certain choices have to be made. These choices concern mainly:

i. the nature of the dimensions on which (or indicators by which) health status is to be measured.

ii. the weights to be assigned to dimensions, or indicators when these are 'traded off' against one another.

iii. the numbers to be assigned to the dimensions or indicators after these have been combined.

Culyer argued that all these choices are always partly technical and empirical and partly a matter of judgement. The circumstances of the case and the observed facts may suggest, for instance, that some indicators proposed for a disability index are redundant because they are subsumed by other indicators. On the other hand, priorities between different disabled groups cannot be decided entirely on technical grounds or even empirically:

> '... choice of the dimensions of an index is partly a question of values, of interpreting the specific objects of policy, and partly a technical question, concerning valid, reliable, economical and reproducible methods of measuring the objects. Just as persons who may legitimately be thought to have a claim on the right to formulate objects of policy ... may have little competence in deciding those matters we have described as 'technical', so those with this latter competence are not necessarily those regarded as having a legitimate right to decide objectives, or dimensions of indexes'. (op. cit., p. 15).

Culyer (op. cit., p. 23 ff) has also given a usefully concise summary of five procedures used to measure 'health status' in individuals. In essence, these combine the trading off of component dimensions and the assignment of overall scores in the way that Mayntz et al.(1978 pp.43-46) recommend. The most straightforward of these methods conceptually has been adopted in research by Patrick et al. (1973) and is described by Culyer as the 'category' method. This involves ascribing numbers to (ie measuring) disability states in such a way that equal differences in the numbers correspond to equal differences in the health and disability states represented in the subjects studied. Obviously, numbers ascribed in this way are intended to produce an (equal)-interval scale of measurement. Further, they will incorporate the value systems with which those ascribing the numbers approach disability. The method therefore provides information about this value system as well as about the actual health status of the individuals assessed. Jette (1980) also comments on the index devised by Patrick et al. using the above procedure. He points out that it is a combined generic and health evaluation index, though its main strength is as the former.

In the present context the main interest of Patrick et al's. 'Index of Well-being' lies in the details of its method of contruction. 'Judges' were presented with cards depicting specific days in the lives of people in various states of health. They were then asked to ascribe numbers to the health states in such a way that the numbers showed how desirable they thought each individual's day was compared with those of others. The judges were, in effect, being invited to bring the value-system with which they approached health matters to bear on an assessment across several important dimensions characteristic of individuals and germane to their health the status. The final result of the judging process was that the ordered health states formed a psychologically valid (equal-appearing) interval scale against which new health states could be matched, provided they were described in terms of the same dimensions of experience.

Another combined generic and health evaluation index incorporating value judgements is described briefly by Jette (1980). This is the 'Sickness Impact Profile' (Bergner et al., 1976) which is intended to provide a profile of the effects of sickness or behaviour. Each item in the profile is assigned a weight derived from a panel of judges indicating its relative severity on a scale of dysfunction. Jette (op. cit.,) considers that this instrument has greater potential than the Index of Well-being as a health evaluation instrument. It is worthy of note that Patrick and colleagues have adapted parts of the Sickness Impact Profile for a study of impaired people in Lambeth Health District, London (Patrick et al., 1978).

CHAPTER TEN

MEASURING DISEASE CONSEQUENCES IN SURVEYS

The effect of context

Any instrument, measure, index or scale has to be designed or adapted to fit the aims of the study within which it is used. Imber (1976), a DHSS statistician, drew attention to this truism when she remarked that any measure of disability is likely to provide findings which will be of practical use only when it is used for the purpose which its designer intended it to serve. Sometimes an existing instrument may be adapted for use in a different context, but a good (ie valid) measuring instrument invariably has clear conceptual and contextual foci and a user whose foci are very different is unlikely to find it of much use.

Imber was discussing disability measures within an in-house paper on disability measurement with administrators as her readership. She had been asked to explain the rationale of certain measuring instruments all of which provided what might be described in fairly general terms as assessments of degree of disability. This task was approached in two stages. First, some basic principles of measurement were discussed, issues of the kind raised in Chapter Eight of the present study being covered. Secondly, about 15 specific measures were commented on. On the whole these fell into two classes; the majority were measures mainly suitable for surveys but a few, like most of the measures discussed in the first part of the previous chapter, were more suitable for making assessments of the disability status of individuals.

It is probably best to regard these applications as ends of a spectrum of usage in which the two ends contrast both in terms of the quantity of data being sought about the subjects of the research and in terms of the required precision of those data.

Imber remarked that, in general, methods and instruments devised for classifying individuals in terms of their disabilities, whether for determining progress or outcome of rehabilitation or for benefit assessment, are usually too detailed and time-consuming for classifying populations. Conversely, systems devised for measuring disability in large-scale surveys often contain a few broad indicators of disability only. In consequence, they are unlikely to provide sufficient information for the accurate classification of individuals when this is necessary. However, it must also be emphasized that a particular instrument may not always lie conveniently at one end of the spectrum or the other. For example, the OPCS self-care instrument discussed in a later section of this chapter is actually more detailed than are some progress and outcome measures used with individuals during and after their rehabilitation.

Errors in survey data

The second contrast mentioned above - that between the precision of the data provided by individualized assessments and the relative imprecision of survey data - can perhaps be most sharply drawn between the population survey for planning and the clinical assessment, the result of which matters intensely to the patient. Silvey (1974) has emphasized this contrast, which is neatly illustrated by the following example provided by Singleton (1978). This is taken from quite a different area of disability assessment from those so far mentioned: the consequences of industrial disease. When the chest X-rays of disabled miners are screened for asbestosis or antimoniosis with a view to providing them with a disablement benefit, the individual plates are studied very carefully indeed by two doctors for up to 20 minutes. But for epidemiological purposes, when it is merely a matter of recording the presence or absence of any kind of disease, the rate of studying the plates can reach several hundreds an hour. Under these conditions, as many as 10 per cent of the

plates could well be misclassified. Yet, providing there is no undue systematic error or bias, the estimates obtained will still be reasonably accurate. The individualized procedure would obviously have been extremely wasteful of time and resources. Rose and Barker (1979, p4-5) provide an equally instructive example from an epidemiological study of oesophageal cancer.

Silvey (1974) makes the following comment in which he contrasts social (survey) research with individualized assessments:

> 'In social research there is not the same need for precision .... If less reliability results, the outcome may simply be to lower an observed correlation .... With fewer items comprising each index, more variables can be covered in a limited interview or questionnaire. Finally, the more varied or monotonous the items, the less co-operation can be expected from each respondent. For these reasons, complex indices are less likely to be used in survey analysis.' (op.cit., p.77)

What Silvey does not mention, however, is that the error of the kind mentioned in the example above - systematic error or one-directional bias - is that which always matters in surveys if it is present to any great degree. Random error might cancel itself out: systematic error never will. An epidemiological or other survey with this kind of error might lead to incorrect estimates, and hence misguided decisions and wrongly-directed public expenditure.

The OPCS Survey of 1968-9

Imber (1976a) wrote her internal DHSS paper on disability measurement mainly in the light of the report of the OPCS survey 'Handicapped and Impaired in Great Britain' (Harris et al., 1971). In spite of the extensive criticisms of its findings by Townsend (1979, Ch.20 passim) many commentators regard the methodology used in this survey very highly indeed (Knight and Warren, 1978). At the same time both its methodology and its results can be used to illustrate the care with which the findings of even the best-

designed surveys must be interpreted in the light of inevitable shortcomings in the techniques employed.

One striking feature of the official report of the OPCS survey is the way in which the authors make explicit the imprecision of some of their estimates of the prevalence of certain kinds of impairment. At the outset of the report (op. cit., p.9) they point out that the questions used to provide estimates of 'the blind, the deaf and the diabetic' were few in number and of such a kind that the numbers suffering from these impairments may well have been seriously underestimated. An examination of the questionnaire used in the survey reveals why this should be so. Its emphasis is, on the whole, on 'skeletal' impairments (WHO, 1980) and the 'personal care', 'locomotor', body disposition' and 'dexterity' disabilities flowing from these. The only question about hearing, for instance, related to one particular 'communication' disability: 'Can you hear ordinary conversation?'. Some guidance was given to assist the interviewers, however, and for the benefit of those conducting the survey, the question had added to it 'with hearing-aid working if applicable'. A rough definition of 'ordinary conversation' was also provided. The responses allowed for were: 'Yes', 'No', and 'Says yes, but difficulty observed.'

This guidance given to the OPCS interviewers seeking evidence of aural impairments and listening disabilities brings to mind other sources of unreliability in surveys generally. One of these is the difficulty of standardizing the conditions under which interviewing and, therefore, measurement takes place. In the OPCS report, Harris et al. were again quite frank about this:

> ' ... our scores are based on the informants' own assessment of ability and will take into account environmental and psychological factors. One woman with arthritis of the hips might say she cannot put on her own stockings at all, while another, using a makeshift gadget, says she performs this operation without difficulty. Similarly, someone in

a wheelchair needs help in getting to the WC because it is upstairs or in a yard, while another with a WC on the same level manages on his own without difficulty'. (ibid, p.262)

Further, in the OPCS survey the question about hearing and, indeed, the questions generally, were phrased in the form 'Can you do ...?' 'Can you hear ...' etc. Whether questions should be phrased in the form 'Can you ...?' or 'Do you ...?' has always been a bone of contention among survey methodologists, and was a point which repeatedly recurred in the post-lecture discussions recorded in the proceedings of the conference on health status indexes mentioned in the previous chapter of this study (Berg, ed., 1973). Patrick et al. (1980) ascribe part of the significantly higher percentage of disabled found in a survey of the disabled in Lambeth conducted in 1978 as compared with the findings of the OPCS survey of 1968 to a changing in the wording of otherwise comparable questions. In 1978 he and his colleagues asked the same questions that were asked in 1968 except that they asked them in terms of performance rather than capacity. Their view is that 'as performance is more readily observable and objective than capacity, perhaps the capacity mode of questioning should be abandoned'. On the other hand, surveys such as the OPCS survey, with its link with Social Security requirements, specifically the Attendance Allowance, often have an explicit aim which requires that people should be asked whether they can do something, not whether they do do it.

However, whatever the reliability or unreliability of its estimates, the OPCS survey was undoubtedly as successful as a well-conducted population survey probably ever is in answering the questions it is designed to answer. In official surveys, even fair precision in estimating numbers through the avoidance of systematic error is invariably a means to an end -

to guide policy and planning. An error in estimated numbers which arises from estimating the wrong concept (a matter of validity) may result in not giving any worthwhile guidance at all. Hence Imber (1976a) followed her remarks about the relative simplicity of measuring instruments used in social surveys with this statement:

> 'If the results of the survey are to be used for the detailed planning of any service, then the scale used must provide frequency distributions compatible with the provisions of that service, but it is not important if a relatively few individuals are misclassified'.

In other words, in any system of measurement used in a survey, the identity of the concepts and categories built into the measuring instruments used must be governed entirely by whether their precision (reliability) and their validity suffices for the use that will be made of the data they provide.

The OPCS disability index

Two important purposes of the OPCS survey as far as health was concerned were:

i. to examine the extent to which the various health and social services were supporting 'handicapped' people, and

ii. to estimate the number of people who might qualify for an attendance allowance.

Hence it was felt necessary to devise a measure which could act as an index of degree of 'handicap' (disability in WHO terms) and which could also identify people who were so severely 'handicapped' (disabled) as to be unable to look after themselves and supply their own basic needs.

With these two basic purposes in mind a complex disability index was devised in which individual items were scored in such a way that account was taken of whether the particular disability measured by each item was 'major' or 'minor'. The scoring also took account of the 'difficulty' that people had in performing the activities specified in the individual items in the measure. Finally, the scores obtained on each item were summed and the disabled people were grouped into categories depending on the score obtained. So that the index could be administered and scored by non-medically trained survey workers, typical examples of disabled people in each category were given in the survey schedule (Harris et al., op. cit., pp.254-262).

It is very easy to criticize the construction and scaling of this index. However, though the rationale given for the choice and weighting of particular indicators is not convincing at every point, alternative choices and weightings could equally well be criticized. As a result of the rather arbitrary decisions made on these matters, the examples of handicapped (disabled) people which serve to define the categories may not seem entirely reasonable to everyone. It may be asked, for instance, whether the bachelor who has to employ a man to bathe and dress him and who at the age of 62 can work full-time is rightly put into the same category of degree of 'handicap' as the slightly younger man who is housebound and has to use a bed-pan and bottle because he cannot reach his outside WC in his wheelchair without help. Another index which used a different weighting system or which employed different criteria of handicap might well put these two men into quite different categories. It may be that the criteria fit well with other aims of the survey, but this is not self-evident.

One of these other aims was, in fact, to estimate numbers of people qualifying for the proposed attendance allowance. As with many other social security benefits, the criteria for the award of this benefit when it was first set up were such that disabled people either qualified for it or they did not. The necessity for estimating numbers in these two clear-cut categories may well have influenced the categorization of handicap in the OPCS survey. In the event, it appears that the survey has not been particularly successful in estimating the number of people so dependent on others by reason of disability that they qualified for an attendance allowance. A subsequent House of Commons paper has described the discrepancy thus:

> 'Although the classification of people by reference to their capacity for self-care might have been thought to be very broadly in line with the basis of entitlement to the allowance, in fact, the use of OPCS data led to an underestimate of the number of expected beneficiaries of the higher rate allowance and to an overestimate in respect of the lower rate'. (House of Commons, 1974, p.4)

It must be emphasized again however, that the benefit as at first envisaged was an 'in-out' benefit, and that the criteria for its award were not intentionally based on degree of disability so much as on need for assistance. This is, perhaps, an instance of a more general problem. The lack of correspondence between the practical criteria for entitlement to a benefit and the 'theoretical' concepts with which designers of measuring instruments and planners of survey research have to deal inevitably leads to discrepancies between estimates and actualities. Hence while Townsend's (1979) critique of the low estimates of the OPCS survey is on the whole justified, his suggestion that better 'functional' scales would solve both the problem of estimation and that of allocation itself needs the most critical scrutiny. This particular issue as it applies to benefits will be discussed further in Chapter Eleven.

The hearing-aid surveys

The designing of survey instruments so that practical questions of planning and policy are satisfactorily answered by the results obtained is obviously not a straightforward matter. The ever-present temptation to the researcher is to pay attention to the phenomena and concepts which are most obviously measurable and to neglect the much more difficult matter of aligning the estimates obtained with the direct requirements of the issues to which solutions are needed. Examples which illustrate this difficulty further are provided by two surveys concerned with hearing impairment.

In 1947 an attempt was made by the Central Office of Information to assess the number of people with impaired hearing who might benefit from the provision of the NHS body-worn hearing aids then becoming available (Wilkins, 1948). As there was no information available on numbers of people with impaired hearing, obtaining these estimates was the obvious first stage of the work. A sample survey was mounted which is in retrospect a model of its kind. The sampling procedures and the classification of hearing disability designed by the researcher combine to give what are generally regarded as highly reliable and useful estimates of the numbers of adult people in England and Wales who in 1947 suffered from hearing disabilities of various degrees.

However, the attempt to derive from these estimates of the prevalence of hearing disabilities an estimate of the number of hearing aids required presented enormous difficulties. In fact, eight estimates (three maximum and five minimum) were made. The highest estimate was determined on the basis of a straight-forward calculation from the unsupported statements of the sample to the effect that they desired an aid. This particular maximum estimate was 800,000. The minimum estimates varied from 220,000 to 370,000; the lowest being 'corrected' for persons where hearing defect was such that it was not judged likely to be

improved by the use of aids. The accuracy of these various estimates can be judged from a later estimate that 600,000 people possessed NHS body-worn aids in 1972 (Davies and Marsden, 1975).

This latest estimate was actually made in the context of a study of the demand for behind-the-ear NHS hearing aid. For policy reasons the estimate was required very quickly so that it was possible to mount a very small survey only. The 'best' estimate was based on the assumption that demand would be such that all those with a body-worn Medresco OL 56 aid would desire to replace this with the new aid. A 'guestimate' of 550,000 was thus obtained. Actually, about one million three hundred thousand behind-the-ear aids had been issued by November 1980 from the time they were made available under the NHS in 1974.

The use of health status indexes in surveys

In the United States, the problems of aligning survey estimates with policy and planning requirements have been extensively discussed during the last decade. Haber (1973) identified the nature of the fundamental problem in terms of the lack of common agreement on both the conceptual basis of disability and the methods by which it should be measured. Nevertheless, in spite of its limitations - especially that it is based on respondent recall - he suggests that the sample survey interview is frequently the only feasible approach towards establishing the relative prevalence and distribution of disability in populations. Attempts have therefore been concentrated on improving the survey instruments used in terms of their reliability and validity.

However, it is also always necessary to link together the epidemiological data derived from surveys and the practical ends of policy and planning which the survey data are intended to inform. The tendency in the last decade, especially in the USA, has been to devise for this purpose new forms of standardized health status index of the kind discussed in the previous chapter, supplemented by systems of weighting indicators or items which incorporate value judgements.

(Berg, ed., 1973; Seigmann and Elinson, 1977.) These indexes have begun to find a use in several areas of health care (Patrick et al., 1980).

More generally, Lerner (1973) has outlined the three main objectives of constructing health indexes as:

i. evaluating 'the effectiveness of current health service delivery systems or programmes, especially those of an experimental nature and financed with public funds'.

ii. evaluating 'the quality of health services provided by medical practitioners directly, on a personal basis, to patients'.

iii. discovering the 'true nature of social reality, independent of any practical application'.

Probably most policy-makers in Britain would agree with Lerner that the first objective is particularly important. Nevertheless the last 'theoretical' objective gives Lerner the opportunity to expound the philosophy behind the construction of indexes of this kind. It seems that this is similar to the philosophy of the WHO when it recommended the construction of a classification of the consequences of disease. Lerner's apologia for describing the health of a population in terms of an index reflecting a combination of physical, mental and social factors presents many of the same arguments as are found in the ICIDH (WHO, 1980). Thus he suggests that (i) the focus of medicine has shifted from mortality to morbidity; that (ii) in a comprehensive assessment of health, emphasis needs to be placed on social factors as well as on physical and mental factors, and that (iii) Maslow's hierarchy of needs can provide a way of conceptualizing the focus of 'disability' indexes.

Other arguments of Lerner remind us of Culyer's (1978) assertion about the role of value-judgements in disability estimation: that issues which often appear to be mainly technical - for instance, how the 'facts' about the nation's

health are being gathered in the General Household Survey - are really permeated with value-judgements. Culyer has drawn out some of the implications of this observation as it applies to the training of personnel in the planning and management of the British health services thus:

> '... it is important to ensure that the sophisticated practitioners of the more mathematical sciences in health planning (such as systems analysis and operations research) are aware of the values embodied in their procedures (which make them more than "merely" scientific) and of the links that exist between these values (and the techniques in which they are embodied) and the ends of policy. It is also important, however, to ensure that the training of less numerate professionals includes a proper appreciation of a marriage between systematic considerations of value in social philosophy and operational quantitative techniques for use in specific planning contexts'. (op.cit., pp.28f)

Validation procedures

Experience with those health status indexes that have been used in policy-making in Britain (Culyer cites that used within the report of DHSS Resource Allocation Working Party (RAWP) of 1976), together with improvements in survey techniques, have contributed to the more sophisticated planning procedures that operate today. In truth, the sophisticated planning has required that survey procedures have also had to become more sophisticated. It is now everywhere realised that the obtaining of 'frequency distributions compatible with the provisions of the service' (Imber's phrase) is never merely a matter of recruiting a few amateur interviewers to ask anyone they come across a few hurriedly thought-up questions and then adding up the responses obtained. The inadequacy of the great majority of the local authority surveys which were intended to provide a framework of estimates of need of health services for local use resulted from following almost that kind of prescription (Brown and Bowl, 1976). Knight and Warren (1978) also comment on these local authority surveys. They suggest that to some degree their deficiencies resulted from a lack of resources. It was perhaps not sufficiently realised, in spite of the guidance provided by OPCS (Harris and Head, 1971, 1974), that translating a set of research questions into anything

approaching a satisfactory survey interview and deciding how to sample a population requires 'the investment of a considerable amount of time and resources in discussions of ... aims and methods, examination of previous research in related areas and designing and piloting schedules' (Maclean and Genn, 1979). In the event it was not surprising that Brown and Bowl rated about 40 per cent of the surveys as 'mediocre' or 'poor' and that about the same percentage of the local authorities were doubtful or critical of the value of the exercise (Knight and Warren, op.cit., p.25).

Once again, therefore, Maclean and Genn's description of how they set about validating the questionnaire used in their study of people whose activities had been limited as a result of illness, injury or impairment is important as a model of good practice (op. cit., p.43 ff). They point out that the usual approach to the validation of a survey instrument of this kind is either to test its power to discriminate between known groups or to examine its relationship to independent criteria. Both these approaches are, of course, 'criterion-related' validation. However, as the main concept on which the survey was focussed ('misfortune') was somewhat broad and flexible, criterion groups could not be clearly identified. Hence the main approach to validation was first to propose carefully-devised operational definitions of the concepts being measured and afterwards to validate them by means of a construct-validation approach directed to explicating the rati onale of the network of definitions, implied definitions and framework which together comprised the theoretical basis of the study.

This procedure was supplemented with 'concurrent' and 'content' validation. The former took the usual form of seeking corroborative evidence that the data obtained were consistent with those obtained from using other measures of similar concepts in other studies. Content validation included an

examination of the total logic of the questionnaire used and was particularly centred on whether the items in the scale of 'interrupted functions' (the main indicator of misfortune) representatively sampled the universe of content of that concept.

All these procedures are in essence no different from those which in modern practice are invariably used in some degree for validating any kind of measuring instrument, whether it is to be used with individuals or groups.

Hence, the problems which arise with both survey and individualized measures are much the same. Perhaps the main underlying problem is that perceived and discussed by Culyer (1978) - that there is no way of evading the value-judgements implicit in discerning the relationship between the 'facts' as derived from instruments employing fairly concrete indicators of health, disability etc., and the much less concrete 'needs', 'requirements' etc. with which planning is concerned.

CHAPTER ELEVEN

THE ASSESSMENT OF DISABLEMENT WITHIN SOCIAL SECURITY PRACTICE

'Disablement'

A word is sometimes required for labelling disease consequences when the whole range of concepts, impairment, disability and handicap needs to be referred to. In English usage, the term 'disablement' is particularly suited to this purpose (Wood, 1980b). Unfortunately, the term has been pre-empted within British Social Security practice to signify 'physical or mental impairment with measurable repercussions' (House of Commons, 1974, p.3 footnote). This usage overlaps with that proposed above, but is obviously not identical to it, so the possibility of confusion arises. On the whole, disablement is used in this chapter in the 'Social Security' sense, that is impairment measured in terms of the functional limitations disabilities or handicaps to which it gives rise'.

Some analyses and critiques of present practice

The most comprehensive analysis of current British Social Security provisions as a whole is Ogus and Barendt's 'Law of Social Security' (1978). The longest chapter of this work deals specifically with Industrial Injuries Benefits (Smith, 1979, also treats these benefits from a similar point of view). Two other chapters respectively consider War Pensions and 'Other Sickness and Disability Benefits'; the latter including a full discussion of the post-1970 non-contributory benefits. A briefer comment on the working of these particular benefits has recently been written by staff of the Social Policy Unit at the University of York (Baldwin et al., 1980). This latter study usefully supplements and updates Ogus and Barendt's material on these particular benefits. It also summarises the main criticisms brought by pressure groups against the benefit system as a whole.

As the next section of this chapter will show, most criticism of the present system focuses mainly on its overall complexity, while the solution most often suggested is that benefit should be paid to any disabled person according to the degree of their disablement. At present, the main determinants of eligibility for benefit are, for example, whether the disablement is 'attributable to or aggravated by service' (War Pensions), whether it arises 'out of and in the course of employment' (Industrial Injuries), or whether the claimant is 'incapable of work' (Non-contributory Invalidity Pension).

Eligibility criteria of this kind might be expected to be framed with the intention of making a sharp division between those who are eligible for a particular benefit and those who are not. An efficient criterion would then be one which is readily interpretable by insurance officers or, failing them, by the Insurance Commissioners and the law. Ogus and Barendt however, point out how seldom this is the case. They describe how the 'classic formulation' of the Industrial Injuries scheme -' arising out of and in the course of employment ' - is 'perhaps the most notorious in the whole of social security law' and 'has been responsible for vast amounts of disputed claims and complex litigation' (op.cit., p.277). It seems, however, that when this problem arises its roots lie in much more than matters of words and phraseology. Rather it is fundamental to the insurance principle of the Industrial Injuries system. Ogus and Barendt (ibid) quote Atijah (1974) to this effect:

> 'The difficulty is inherent in the system; it has nothing to do with the "meaning" of ... words ... The difficulty is inherent in the concept of insurance against special "employment" risks.'

It seems doubtful, therefore, whether principles and methods of measurement as discussed in the present study are likely more than a marginal relevance to a discussion of the benefit system as it exists at present. It may be that only when the degree of disablement has actually to be assessed will scientific measurement procedures have any direct contribution to make to benefit assessment. When they are

relevant, however, their application might just lead to insights which would increase the efficiency of present methods of assessment for certain benefits; War and Industrial Disablement Pensions for instance. However, in spite of doubts about the general applicability of measurement principles and procedures, some consideration of wider issues will be attempted before particular benefits are discussed.

The present system and its possible replacement

The philosophical basis of a considerable part the present benefits system as it applies to sick and disabled people is probably most clearly expressed in the House of Commons paper (1974) already cited (p.140). This paper reviews the progress of the non-contributory benefits introduced following the Chronically Sick and Disabled Persons Act of 1970. It is suggested that in introducing those benefits the declared policy of government was to isolate specific needs and to satisfy them with benefits:

> 'There must be priorities. The greatest needs must be identified and met first on the basis of a sound programme of cash benefits and services which takes account both of the practical limitations of detailed assessments of need and of the choices expressed by disabled people themselves' (House of Commons, 1974, p.17).

Unfortunately, some critics feel that the practice did not entirely fit the principles. They are inclined to suggest that the new benefits and services could not form a sound programme because they had to be fitted into an unsound existing system and merely added to its complexity. The result according to Baldwin et al. (1980) is:

> 'an accumulation of benefits awarded on criteria deriving from different principles, with different and sometimes conflicting purposes, assessment and administrative systems .... The compexity of disability benefits is interwoven with all the complexities of the general system of income maintenance, of local means-tested benefits and services and of occupational welfare systems'.

Baldwin and her colleagues support these assertions by Blaxter's findings (1976) that, in 1972, there were 59 agencies in one city helping people with sickness and disability problems, by the Economist Intelligence Unit's identification of 55 central government benefits applicable to disabled people (Simkins and Tickner, 1978); and by the gathering together by the Royal Commission on Civil Liability and Compensation for Personal Injury (1978) of 122 different DHSS leaflets explaining benefits for the disabled.

Similar arguments against the present system have also appeared in other sources (eg Sainsbury, 1974; Townsend, 1979). However, Simkins and Tickner's critical study probably contains the most extensive and certainly the most colourful criticisms. The present benefit system is described as 'a ragbag of provisions, based on differing, sometimes conflicting and anachronistic principles, which have not been sorted since 1941' (op.cit., p.17). The study criticises particularly the administrative costs and structure of the system: the 'piecemeal' legislation involved is said to have produced a 'resulting tangle' of organisation and methods. It ends with some ideas for removing what are regarded as the worse features of the present system and a plea for a 'wide-ranging, independent restructuring' in terms of a taxable payment as of right to 'handicapped' people by virtue of their disablement, together with a supplement for the additional expenses of disabled living.

Another statement of an alternative to the present system appears in a pamphlet produced by the Disability Alliance (1975). It is suggested that 'functional' criteria expressed in terms of specific disabilities could provide a method of wide application for assessing disablement. Some support for this contention has been provided by Sainsbury's (1974) trial of such a method, but probably more is provided by the cogency of her arguments. She argued that inconsistency often occurs just because the various provisions for income maintenance of which

disabled people can take advantage have been established in response to specific problems, not always directly connected with disability, as they have been recognised at specific points in time. As a result, no single rationale underlies the diversity of methods of assessing disablement. In fact, 'the method of assessment used varies with the benefit in question'.

Sainsbury proceeded to explore the possibility that a particular concept of disability, conceived of as 'incapacity to perform certain activities associated with daily living' could be applied operationally in terms of an index of key activities to provide acceptable means of rationalising the present complex system. Nine activities were finally included in the index and each task or activity was scored on the basis of 'no difficulty' 0; difficulty 1; unable to complete 2. The maximum score was therefore 18 and a high score indicated severe disability. Examples of the application of the index were given and some of the problems associated with its use were discussed.

Quite apart from the general criticisms of indices of this kind expressed in the previous chapter, it is quite clear that the amount of empiricial work that could be carried out by one person within the limit of the resources allocated to the study was quite insufficient to answer the many questions that need answering before the feasibility of a new system of this kind can be determined. The main strength of Sainsbury's study lies in the arguments she deploys to support her conclusion that the present system of assessments, in which criteria are applied which reflect the origin of benefits and the political and social pressures which have determined their development, should be replaced by an overall assessment of activity restriction since this could be the most valid assessment from the point of view of disabled people themselves:

> '...however disabled persons are categorised in social policy, they tend to see disability in similar terms, namely, the consequence which it has for their capacity to pursue the aspirations common to most persons in our society. In their terms, therefore, the effectiveness of social policy as it applies to disabled persons is to be seen in the success with

which it operates in providing for them the opportunity to pursue their aspirations. Hence, a measure of the degree to which disabled persons are forced to depart from social norms provides a basis for evaluating social policy and need from a disabled person's point of view'. (op.cit., p.100)

In presenting her central argument in this way Sainsbury seems to be suggesting that the most basic question to set against ways of measuring disablement within the benefit system is not really empirical - which method is most efficient and reliable? Rather the basic question is 'political' - whose value system should govern the methods of assessment by which disabled people qualify for benefits?

Townsend (1979) has probably pressed research evidence to the limits of its power to answer this political question. Thus he draws on the results of both Sainsbury's work and that of the OPCS survey of 1968-9 to reinforce his arguments for the use of a 'functional' disability index to determine eligibility for benefits. In particular the ability of the OPCS index discussed in the previous chapter to distinguish degrees of disability has enabled him to suggest that assessing eligibility on this basis might lead to a fair distribution of resources than the present system. He holds the view that by using functional criteria:

> 'Attention is called to the wide range of different effects of disability, with the possibility that social resources will be mobilized less erratically to deal with them or to offset them. And although the risks of misclassification must be considerable, degrees of disability are more accurately identified, so that fairer methods of compensation are devised, and benefits and services can be allocated according to some scale of priorities'. (op.cit., p.695).

In the absence of proper feasibility studies and controlled trials to test Townsend's assertions, however, this argument seems, at best, inconclusive. Is it really 'fairer', for instance, to assess benefits according to degree of 'disability' or according to, say, loss of earning capacity after rehabilitation - a basis which applies in many European countries (DHSS, 1972)?

Criteria of eligibility for benefits

To receive benefit of any kind within the present system the claimant has to satisfy certain conditions which vary from benefit to benefit. These conditions are, of course, carefully stated in the regulations appertaining to each benefit. Nevertheless, as Ogus and Barendt (op.cit.passim) have pointed out, even social security officers sometimes have difficulty in applying the regulations for some benefits to particular cases. To settle these recourse must be had to the courts or to the National Insurance Commissioners. The main problem from a measurement point of view seems to be that the rules for entitlement do not always suffice to make a sufficiently clear division between applicants who qualify and those that do not. To some extent this lack of clear criteria, even if it is not inevitable, can be justified. It enables reasonable consistency to be established through the development of case law, while at the same time a degree of flexibility enabling justice to be done in individual cases is tolerated. Ogus and Barendt (ibid; p.469), remark that this argument was used in the Department's representations to the National Insurance Advisory Committee concerning the Housewives' NCIP. Apparently, the Committee itself thought it 'likely that the adjudication difficulties with the new benefit will be greater than with other incapacity benefits', but was 'not persuaded that these would be reduced if the regulations were to attempt to provide a much more detailed definition [of incapacity]'. (Report on Draft Regulations, para 12, cited by Ogus and Barendt, ibid, in footnote.)

In this situation, it might be just possible to invoke measurement principles to indicate a possible solution, The main principle that might be applied is,at least, reasonably simple to state. It is that in a system under which claimants either qualify for a benefit or do not qualify, the number of serious misclassifications will depend entirely on the precision of the criterion determining qualification. In other words, a precise criterion is essential in benefit arrangements in which people are either wholly 'in' or wholly 'out', if problems of classification are to be avoided.

It also follows that when an in-out system is compared with a graded system in which claimants can qualify for a partial benefit, perhaps by satisfying a less rigorous criterion, the in-out system is likely to lead to fewer misclassifications than one which is graded. However, the misclassifications are liable to be more severe in the sense that they will affect the claimant more drastically - he gets all or nothing.

In another context, Ebel (1965) has calculated figures which illustrate these assertions. He has shown that if 1,000 people are assigned to one of five grades by means of a method which is technically capable of putting them into rank order with very high reliability (0.90), then almost a quarter of them will be misclassified by the relatively crude grading. Fortunately, when five grades are used the misclassifications which take place with a method of this reliability will be of no more than one grade and therefore not really very serious. However, if there were only two grades, although only about 90 of the 1,000 people would be likely to be misclassified, the misclassifications are obviously much more serious for the persons concerned. Hence, while measurement principles serve to strengthen arguments for criteria which are designed to be as clear as possible, they also make a case for devising graded benefits where these seem appropriate.

Application of measurement principles to the post-1970 benefits

Ogus and Barendt's arguments (op.cit., Ch.4) suggest that the criteria for most of these benefits are not always likely to lead to clear decisions. It seems, for instance, that the meaning of almost every clause of the conditions*

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* The conditions for the award of Attendance Allowance and relevant Regulations relating to the Mobility Allowance are stated in an Appendix to this Chapter.

for the award of Attendance Allowance has been disputed (ibid pp.173-6). Similarly, they show that the basic statutory test of entitlement to the Mobility Allowance - interpreted in the light of the Regulations*, leaves a great deal to the discretion of the insurance officer, the medical authorities and the Commissioner (ibid, p.185). With benefit of hindsight, one might ask whether criteria would be framed more clearly if pilot studies of different versions of conditions and regulations were carried out as a matter of course, so that fewer difficult cases would need to come before the Insurance Commissioner and the Courts.

The second principle, which suggests that graded benefits with different rates of allowance might reduce the number of 'hard cases' and, therefore, appeals, can be applied most clearly to recent discussions of the so-called Housewives' Non-Contributory Invalidity Pension (HNCIP). (Unfortunately, the flat-rate form of Attendance Allowance was not in existence long enough before it was replaced by a graded allowance for the figures on numbers of benefits awarded and appeals made to be informative about the effect of the replacement.)

The Housewives' Non-Contributory Invalidity Pension

The HNCIP is a flat-rate benefit awarded to women who fulfil certain conditions relating to residence with or assistance from a man and who as a result 'of some specific disease or bodily or mental disablement' is 'unable to perform to any substantial extent, or cannot reasonably be expected to perform to any substantial extent, normal household duties' or where she fails to satisfy this condition only because she obtains 'substantial assistance from or supervision by another person'. (Social Security (Non-Invalidity Pensions) Regulations 1975, Reg 13A.)

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* The conditions for the award of Attendance Allowance and relevant Regulations relating to the Mobility Allowance are stated in an Appendix to this Chapter.

In determining the question of incapacity for normal household duties the authorities are to have regard to three main considerations: the nature and severity of the claimant's disability, the size and composition of her family and the physical environment in which these duties would need to be performed, including the facilities available (National Insurance Advisory Committee Report, 1977, para 16). All these criteria obviously admit of different degrees so that assessment has to be based on measurements of some kind made in three distinguishable dimensions. As arguments used in Chapter Eight have shown, this task is by no means impossible if degrees of qualification for benefit are permitted. What is almost certainly impossible, however, is to establish a clear-cut 'in-out' criterion for qualification on this basis. The problem is compounded by the use of both a comprehensive self-completed claim form, which asks questions relating to the claimant's household circumstances and her ability to cope with various tasks, and a doctor's report on functional abilities based on a medical examination.

Baldwin et al. (1980) summarise the three main criticisms commonly made of the working of this benefit. First, 'it perpetuates outdated assumptions' about the role of married women in society. Secondly, the household duties test discriminates against married women because they have to satisfy more stringent conditions than groups claiming NCIP. Thirdly, the household duties test is difficult to apply 'equitably'.

If measurement principles are relevant at all, they will be relevant only to the third area of criticism and then only if one is willing to substitute the more neutral 'reliably' for 'equitably'. As Baldwin and her colleagues imply, to ask a claimant to assess her own incapacity in relation to household duties is tantamount to asking her to plead more disabled that she actually is, an idea repugnant to the conscientious and obviously leading to unreliable data. Similarly, one must question whether doctors can be expected to do as they are required, and to supply reliable data on the ability of women to do household tasks in the variety of circumstances presented for examination.

Generally speaking, medical practitioners are experts on impairment, not on disability (AMA, 1971).

These and other criticisms of the working of the benefit have recently been considered by a National Insurance Advisory Committee (1980). Their report is particularly interesting because it includes the Department of Health and Social Security's replies to the criticisms as well as the recommendations of the Committee. As regards the Department's replies, one in particular may be relevant in the present discussion:

> 'it is rarely possible for those not in possession of all the available evidence to judge the consistency of decisions' (op.cit., para 26).

While everyone must agree with this statement, measurement specialists are likely to find it unsatisfactory in its implications. Certainly consistency, a form of reliability, is at issue, but one wonders whether, in fact, the evidence available to enable judgements of consistency to be made is itself reliable. Was there, for instance, a trial of versions of the self-report test so that the most reliable one could be selected? Were consistency co-efficients between doctors and between patients obtained in trials or during use? Was the requisite technical advice obtained before the test was introduced?

Nevertheless, it may be that these are side-issues. As before, the basic measurement problem relates to the appropriateness of tests capable of fine grading to an 'in-out' benefit such as HNCIP. Again, calculations of Ebel (op.cit) are relevant. He has worked out figures which show that when tests of this kind are used to provide a criterion which permits only an in-out grading then the consistency of grading measured in terms of a reliability coefficient is bound to be substantially reduced. Some of Ebel's figures are shown in Table 11.1 (In Appendix, p.157).

Perhaps the common-sense comment of Baldwin and her colleagues on the HNCIP makes the same point adequately enough: '... whereas there is a fairly clear dividing line between fit and unfit for paid work, a person is never really 'in' or 'out' of housework unless disability is total'. It follows, therefore, that if the tests for eligibility are to work even reasonably well, this particular benefit should be graded.

Industrial Injuries and War Pensions Assessment

Compared with the non-contributory benefits, determination of eligibility for these long-established benefits depend on a large body of case-law, some of which has resulted in quite fundamental changes in the criteria for eligibility to ensure greater clarity. Nevertheless, it is at this first stage that problems still arise and once entitlement has been established problems are relatively few. At the second stage of the assessment process, when degree of disablement is established and where measurement principles are more obviously relevant, there is neither the disadvantage of having to rely inappropriately on fine assessments of degree of disablement to establish basic eligibility for in-out benefits, nor is any difficulty caused by the inability to match amount of benefit to assessed degree of disablement.

The general principles of assessing industrial disablement are summarised by Ogus and Barendt (op.cit., p.309). All disabilities incurred as a result of relevant 'loss of faculty' (impairment) are taken into account. The loss of faculty is that:

> 'which a claimant may be expected, having regard to his physical and mental condition at the date of the assessment, to be subject during the period taken into account by the assessment as compared with a person of the same age and sex whose physical and mental condition is normal'. (Social Security Act, 1975, Schedule 8, para 1(a)).

When it is loss of faculty in the sense of impairment which is actually measured, assessment is likely to be reliable. A comparison of the types of measure suggested for impairments and disabilities in the WHO (1980) proposed classifications shows that impairment assessment is relatively straightforward because it is a matter for scientific measurement or for expert judgement. This straightforwardness can also be observed in the matching of 'typical' impairments and suggested percentage disablements listed in schedules appended to the Handbooks for Medical Boards (HMSO, 1970; DHSS, 1976).

The provision of schedules to assist Industrial Injuries and War Pensions' assessors was particularly commended in the report of the Committee on the Assessment of Disablement (McCorquodale Committee, 1965). That report would have carried more conviction, however, if there had been more signs in it that the Committee was aware of the naivety of the existing schedules and consequently had anticipated the growing need for the regulation (eventually promulgated in 1975) governing the assessment of conditions not prescribed in the schedule (Social Security (Industrial Injuries) (Benefit) Regulations 1975 Reg 2(7)). Under this regulation the assessment of unprescribed conditions is a question of fact so that the decision of the medical authorities will be regarded as conclusive. It is only required that they 'have such regard as may be appropriate to the prescribed degrees of disablement' of the injuries specified in the Schedule. As Ogus and Barendt (op.cit., p.811) point out, this means it is now wholly within the competence of the medical authorities to compare the loss of faculty with those listed in the schedule and to select an appropriate degree of disablement to suit the individual case. This regulation seems to meet the general criticisms of schedules of this kind put forward at length by Kessler (1970) as well as the more particular criticisms of Sainsbury (1974).

Ogus and Barendt (op.cit., p.311ff) also discuss other criticisms of the methods of assessment for industrial disablement and war pensions benefits. They point

out that the principle of using loss of faculty as the measurable entity is not without critics, and that it is sometimes felt that claimants would be better served if the social and psychological effects of impairment (handicap) formed the basis of assessment (Blaxter, 1976, p,187ff). However, certain allowances - Constant Attendance Allowance, Hospital Attendance Allowance, Exceptionally Severe Disablement Allowance, Special Hardship Allowance, etc. - make provision for persons particularly disadvantaged by circumstances. The criticisms therefore tend to merge into that which is used against the benefit system generally - that it is 'piecemeal', 'complex' and so forth.

The American Medical Association Scheme

From time to time, comparisons have been made of aspects of the Social Security systems of different countries and in recent years some detailed observations of systems within the EEC and Europe generally have been made. The report compiled by DHSS administrators (DHSS, 1972) cited at several points in this study is a typical example. Such studies are usually primarily descriptive, necessarily dealing with basic matters or organization and classification. They do not generally aim to evaluate systems in terms of the measurement issues raised in this study. However, they do suggest that the system of other countries are often similar to our own in thier 'prescientific' orientation, no overt application of measurement principles being attempted. In fact the only scheme which appears to apply these principles in a way which might provide insights for parallel parts of our own benefit system is the American Medical Association's scheme for the assessment of permanent impairment (AMA, 1971).

From a measurement point of view this scheme is particularly interesting because it represents a sophisticated attempt to arrive at consistent assessments of disablement for insurance purposes under conditions which are all against consistency. It is suggested that, by means of the guidance given, any competent and reasonably experienced doctor will reach an assessment of almost any condition which would agree with that of other doctors in other States of the USA. The scheme is outlined in the various AMA guides for evaluating 'permanent impairment'. These were drawn together in 1971 into one volume, the preface to which points out that the medical evaluation of 'permanent impairment' is only one factor, albeit the main factor, in evaluating 'permanent disability':

> 'In the last analysis, this [the evaluation of Permanent Disability] is an administrative and not solely a medical responsibility and function. Evaluation of permanent disability is an appraisal of the patient's present and future ability to engage in gainful activity as it is affected by such diverse factors as age, sex, education, economic and social environment, in addition to the definite medical factor - permanent impairment. The first group of factors has proved extremely difficult to measure. For this reason permanent impairment is in fact the sole or real criterion of permanent disability far more than is readily acknowledged'. (op.cit., p.111, material in brackets added).

'Permanent impairment' approximates to what is understood in Britain as 'loss of faculty' and 'permanent disability' to what is understood as 'disablement'. Under this system guidance as to what constitutes different levels of permanent impairment is not provided by relatively simplistic lists of 'loss of faculty' equivalents, however interpreted. Instead, depending on the particular type of impairment or medical condition, evidence of loss of structural integrity, loss of functional capacity, persistent pain, inability to perform the activities of dialy living (especially for diseases of the nervous system) and loss of physiological, psychological, personal and/or social adjustment (especially for mental illness) are all taken into account in evaluating impairment. Examples are given and

suggestions are made for the range , in terms of a percentage, of assessments of physical and mental impairment relating to specific conditions. In addition, where there is more than one impairment, directives are given about their combination into an assessment of 'impairment of the whole man'. However, it is suggested that the physicians task ends with his report on impairment and that the final determination of 'permanent disability' must take other social and economic factors into account before a decision is made as the claimant's entitlement. Hence, in the American system as in the British, the physician is not the only professional involved in assessing disablement.

Kessler (1970) has indicated the American view of the appropriate balance between medical and administrative responsibilities. He seems worth quoting at some length:

> 'Although the physician is able to estimate the nature and degree of a medical impairment, nothing in his training and little in his experience have prepared him for the task of evaluating the psychological, social and economic consequences .... He is trained to observe defects and to measure variations from the normal, but no system of pathological evaluation includes estimation of the capacity to work and other associated non-medical factors ....
>
> The administrator or judicial official is usually better qualified to evaluate the non-medical factors and to place them in proper perspective. He or she should be informed about the social consequences of impairment. However, this person may have little or no competence in the medical field and must accept more or less on faith the medical assessment of the condition. Likewise, if the administrative official judging the claim of an injured worker or a disabled person has had no personal occupational experience, this individual is in no better position than is the physician to evaluate the social, economic, or vocational results of the physical or mental impairment. In such cases, his function is to weigh evidence. Self-serving declarations by the claimants must be supplemented by expert information from accredited sources. The interests of the injured person and of his community are served best when medical and non-medical experts combine their knowledge to make a realistic evaluation of disability.' (op.cit., p.25 f)

The key to an understanding of the AMA scheme is to recognise that American 'permanent impairment' is approximately equivalent to British loss of faculty. Many kinds of impairment and, therefore, losses of faculty are nowadays susceptible of both precise definition and exact measurement (AMA, 1977 p.iii). Other kinds of impairment are not directly measurable but may be manifested under measurable aspects of disability. For instance, when one is aiming to measure disablement resulting from mental illness, one might aim at measuring, or at least estimating, 'disability' along psychosocial dimensions such as 'ability to care for oneself' or even 'confusion'. In such cases, empirical measures of proven reliability and validity may sometimes be useful, at other times informed and expert judgement might well be the only way to reach the basis for an equitable assessment.

Appendix

CONDITIONS FOR THE AWARD OF ATTENDANCE ALLOWANCE (SOCIAL SECURITY ACT 1975 SECTION 35 (I))

The 'day' condition is that the claimant:

> 'is so severely disabled physically or mentally that, by day, he requires from another person either (i) frequent attention throughout the day in connection with his bodily functions, or (ii) continual supervision throughout the day in order to avoid substantial danger to himself or others'.

The 'night' condition is that he or she

> 'is so severely disabled physically or mentally that, at night, he requires from another person either (i) prolonged or repeated attention during the night in connection with his bodily functions, or (ii) virtual supervision throughout the night in order to avoid substantial danger to himself or others'.

MOBILITY ALLOWANCE REGULATIONS (1975), REG 3(1)

A person shall only be treated ... as unable to walk or virtually unable to do so, if his physical condition as a whole is such that, without having regard to circumstances peculiar to that person as to place of residence or as to place of, or nature of, employment:

a. he is unable, or virtually unable, to walk; or

b. the exertion required to talk would constitute a danger to his life or would be likely to lead to a serious deterioration in his health.

Table 11.1 Effect on the reliability co-efficient of reducing the number of grades

		Reliability co-efficient			
No. of grames	10	0.92	0.87	0.78	0.68
	5	0.85	0.80	0.71	0.62
	2 (in-out)	0.63	0.60	0.53	0.43

CHAPTER TWELVE

RECAPITULATION OF MAIN THEMES

Origin of the present study

The origin of this study lay in a proposal put forward in April 1977 within the Social Research Branch of the DHSS, outlining the need for an "Explanatory Study on the Assessment and Classification of Handicap". The main purpose of such a study lies in the use of the term 'explanatory' to describe it. It implies that clarification and analysis of relevant material - research studies and the like - should be attempted. Such studies were available in profusion at that time and were still being produced during the life time of this study. Nevertheless, clear themes have emerged and the division of this study in three nearly equal sections - terminology, classification and assessment - indicates the author's view of an appropriate organisation of the available material.

One expected result of the study was that policy makers should be better able to assess the relevance of academic research to their concerns. It was observed that much of this research is unco-ordinated, that the pre-suppositions of studies superficially similar in approach often differ in ways which ensure contradictory results, and that researchers can be as idiosyncratic as others in their use of 'disability' terminology. In consequence, the study reported here is conceived by the author as, in part, an attempt to explain some of the more straightforward aspects of the approaches and methods used by researchers who are investigating the consequences of chronic disease.

However, the records of discussion within the DHSS prior to 1977 show that the initiatives which led to the drawing up of the research proposal were much more than a reaction to a confusion of ideas emanating from a chaos of research findings. In Britain, order was already being established by the

work, based as it was on careful definition, of the OPCS in its survey of 1968-69 (Harris et al., 1971). It was appreciated that the methods used in this survey provided a sound base from which the merits of more recent attempts to classify and assess both individuals and groups could be evaluated. At the same time, it was realised that the important differences of purpose and scale between individualised and group assessment/classification systems meant that in both cases technique must always be subordinated to purpose.

In fact, the author sometimes feels that the records could indicate that solutions to the problems to which he has drawn attention would eventually have emerged from within the Department without the aid of this study. In particular, in reading the summaries of discussions which took place in late 1976 and early 1977, it is evident that the potential importance of the WHO proposals for a classification of disease consequences was also being recognised even though it was only then in draft form (Wood, 1975). It was clear that there was a willingness to wait until these proposals had attained their final form before detailed recommendations on the classification and assessment of all aspects of the consequences of disease relevant to the work of the DHSS and the health service were made.

The OPCS survey of 1968-69

As is suggested above, by 1977 a major clarification of concepts relating to the consequences of chronic disease had already occurred through dissemination of the findings of that part of the OPCS survey of 1968-9 which related to the numbers and needs of 'handicapped' people. At the very least, this survey demonstrated the sheer size of the problem. Over a million adult persons were reckoned to be 'handicapped', and in addition, approaching two million were 'impaired'. Women substantially outnumbered men, mainly by reason of their relative longevity, in both categories.

Numbers, however, depend on definition, so that the careful distinctions made in the 1971 report between impairment and handicap and between degrees of handicap are crucial to the significance of these findings. There is no doubt that the attempts made in that report to devise definitions of health states able to reflect the complex realities of experience have been reasonably successful and have served to clarify the thinking of many health workers during the last decade. For this reason alone they are worth some further analysis.

At first sight, the conceptual distinctions made in the report are fairly clear as regards the use of the terms 'impairment' and 'handicap', but less clear about 'disability'. At the outset of the report, it is suggested that impairment should be regarded as a state of defect of limb, organ or mechanism of such a degree as to imply functional limitation (disability), and also as a state in which a limb or part of a limb is absent. Under this definition, a person without a limb or part of a limb would also be regarded as impaired but not necessarily as disabled. A person with a defect of structure or function, however, is only to be regarded as impaired if he or she is also disabled. This seems clear, though rather complicated.

The state of handicap was said to occur when a person's impairment and consequent disability is sufficiently severe as to give rise to a state of disadvantage or restriction of activity. Operationally, however, handicap was defined only in terms of restriction of activity. To define it in terms of disadvantage, reference would have to be made, for instance, to people's experience of the broader conditions under which handicap might arise, such as bad housing and insufficient education, and to the interaction of these with disability states. Defining handicap in terms of capacity or performance -

the inability to perform acts of self-care (washing, dressing and so forth) - or of the extent of the care and support people are likely to require for these activities makes the concept manageable but results also in a new range of problems, mostly conceptual, but with some practical implications.

The immediate result of applying the OPCS scheme of terminology seems to be that the extent of health-related disadvantage in the community is liable to be under-estimated. It is as if a notion of the person as he or she is 'in himself or herself' (cf. Agerholm's 'intrinsic handicap') is firmly kept in view, so that complications will be avoided when the appropriate 'disablement' label is applied. Persons who have lost a limb will be described as impaired, disabled, handicapped or all three. Persons who suffer from a defect are impaired only if the defect issues in functional limitation or disability. They are handicapped also only if they experience self-care difficulties, as measured either by inability in performance or by the amount of care required. In short, the context in which performance or care are required is not enquired into too closely. This has the advantage that fairly clear-cut distinctions can be made; the disadvantage is that they do not reflect real-life complexities.

It may be argued, however, that the main categories used in the OPCS survey, those of impairment and handicap as defined above, also serve to distinguish the relatively objective medical focus of health care (impairment) from its consequences expressed in terms of what people can or cannot do or the support they require (OPCS handicap). However, it may be questioned whether this notion of handicap is sufficiently broad even for health-related purposes. Certainly, in terms of the declared scope of the OPCS survey it is not. The Introduction to the official report (Harris, op. cit.) points out that 'health and welfare' were interpreted widely. It was felt that 'no study of the

handicapped would be complete without examining medical aid and advice, and ... the whole housing situation of the handicapped'. The study also covered employment. In fact, five main fields of interest emerged, and three of these obviously presuppose a wider definition of handicap than that actually used for counting the 'handicapped'.

The five fields are described as:

i. the cause of impairment, the extent to which impairment results in handicap as far as self-care is concerned, and the extent to which handicapped and impaired people are helped by the various authorities.

ii. to what event impaired and handicapped housewives can carry out their duties,

iii. their housing conditions,

iv. the effect of handicap and impairment on ability to get suitable employment, and

v. the effect of handicap on social life and leisure activities.

The first of these fields - the cause of impairment, the connexion between impairment and self-care, disability, the services received by people with impairments and self-care difficulties - is obviously of broad interest to personnel in all health and some social services. The second field is clearly focussed on laying foundations for costing a possible housewives' pension, such as the HNCIP discussed at some length in Chapter Eleven. The last three fields, however, just as obviously relate to dimensions of disadvantage where health concerns are bound to interact with housing, employment, education, etc., which lie outside the operationalised OPCS 'health' definition of handicap.

It is mainly for this reason, that the OPCS definition of handicap as operationalised in the survey does not really extend even to all the health-related aims of that study, that the final WHO scheme of classificati on of impairments, disabilities and handicaps is commended. It seems especially important that in this scheme, 'disabilities', clearly defined in terms of performance in a wide range of activities and hence corresponding to handicap as operationalised in the OPCS scheme, are distinguished from 'handicaps', defined in terms of specific disadvantages which though arising from impairment and disability are experienced in a wide range of situations or roles. Some of these situations and roles fall outside the health sphere, but Departments of Government other than the DHSS have welfare responsibilities so the 'Handicap' section of WHO classification is of concern to them also.

The WHO Classification of Impairments, Disabilities and Handicaps

The extent of the differences between the terminological scheme underlying the WHO classification of 1980 and that of the OPCS scheme of ten years earlier is easily underestimated. The inevitable similarities in the actual words used and the obvious debt of the former to the 'sequences' of the latter tend to hide some quite fundamental changes in moving from one to the other. One such difference depends on the quite different purposes which the schemes were and are intended to serve. The OPCS terminology was drawn up quite specifically to estimate numbers of 'impaired' and 'handicapped' persons over 16 years of age in different categories of need. Hence, it is people who are counted and classified. The orientation of the WHO scheme is primarily conceptual and theoretical even though it has applications which potentially extend beyond the use of the OPCS scheme. It is, in fact, designed for all purposes in which record making and keeping play a part. Hence, in the WHO scheme, emphasis is put not on classifying

persons but on classifying their health states in terms of their impairments, disabilities and handicaps. It is open to different agencies to classify all or some of these aspects of disease consequences as seems appropriate to them. Each agency can develop the kinds of assessments which best serve its purposes on the basis of one or more of the three classifications.

Another important consequence of classifying health states rather than persons is that writing or, when the scheme has been fully assimilated, even speaking of individuals or groups as being 'disabled' etc., is discouraged: persons have or have not specific impairments, disabilities or handicaps as the case might be; to describe them broadly as 'impaired', 'disabled' or 'handicapped' is liable to be so imprecise as to be misleading and inaccurate. One specific consequence of this change in approach is that the assessment of people should become less a process of objective labelling with possible stigmatizing consequences, and more a process of objective assignment to predetermined classes - those specified in the ICIDH. Perhaps an example will help readers to appreciate the significance of this change. When a child is born with impairments as a consequence of spina bifida say, one reaction could be immediately to label the child as 'handicapped' and to set the appointed medical and caring processes in train. But a more deliberate and careful approach is possible and might permit more flexibility. Certainly, the child has an impairment and medical expertise should investigate it, but it has not yet a disability, since the few things a very young child without impairments can do, this child might well also be able to do. Gradually, the child might acquire disabilities, but by interventions of various kinds, from parents as well as professionals, these disabilities may be kept to a minimum both in number and degree. Similarly with handicaps; these can be evaluated precisely by applying the scheme of

classification of handicaps so that appropriate interventions and care for this particular child can be devised.

Other differences between the OPCS and the WHO approach have been introduced within the previous section. In the WHO scheme a clear distinction is made between disabilities in terms of performance in specified activities and handicaps in terms of disadvantages in specified circumstances. Also a wider range of activities is subsumed under possible disabilities, and handicaps outside the conventional health field are allowed for. As a result, the WHO classifications seems to have the potential to carry future surveys and other kinds of study more deeply and precisely into disease consequences conceived of in wide terms.

In the present 'trial' version of the WHO handicap classification, the six 'key' dimensions are designated, following Maslow (1954), as 'survival roles'. A theoretical approach of this kind has distinct advantages. The use of these handicap dimensions in future surveys and other kinds of study will provide evidence of the construct validity of this part of the classification and therefore a test of the theory on which it is based. In fact, the six dimensions are claimed to be universal, so that they can, in principle, be applied in any country with its particular circumstances. However, modification of the designated dimensions can gradually take place as experience in using them grows. Certainly this possibility is envisaged: 'The six major survival roles by no means exhaust the possibilities of disadvantage ...' (WHO, 1980, p.184).

Future uses of the ICIDH

The best brief explanation of the WHO proposals so far available, is an article by Wood, the consultant to the ICD Unit at WHO, Geneva, for the

development of the classification (Wood, 1980a). In this article, Wood reviews (i) the scientific justification for concern with disease consequences, (ii) the concepts in terms of which these consequences can be appreciated, (iii) the historical development of data about chronic and disabling conditions, (iv) the value of such information to management, and (v) the application of the proposed scheme of classification. The arguments deployed under (iv) seem of particular interest to administrators and, though they have all been touched on at various points in earlier chapters of the present study, Wood's presentation provides a convenient focus for a summary here.

First, the conceptual distinctions between impairments, disabilities and handicaps broadly correspond to real-life distinctions between aspects of the provision made for health care. Thus,according to Wood,'impairments are primarily the concern of medical services, disabilities of rehabilitation facilities, and handicaps of social welfare provisions'. As is suggested above, handicaps as defined in the WHO classification are of concern to workers in many areas of social policy. Hence, as Wood suggests, 'the IDH classification scheme helps to display policy options more explicitly'.

Secondly, Wood suggests that the ICIDH manual provides a framework for the collection and standardization of statistics relevant to policy and for monitoring the progress of chronic and disabling conditions in individuals and groups. There seems to be considerable scope for applications of the latter kind during episodes of treatment and rehabilitation.

A third group of uses to which Wood draws particular attention is that of screening. Stated examples of purposes for which screening might be useful

are job or school placement, rehousing people with locomotor, personal care and body disposition disabilities, and identifying vulnerability in the elderly. Wood suggests that these tasks can best be approached by using the disability code to determine both a profile of the individual's functional abilities and a reciprocal specification of the environment with the intention of identifying discrepancies. Singleton (1979) has proposed a similar approach in work relating to employment disability recently completed for the EEC. In both approaches the remedy would be to alter the environment to reduce disability rather than to impose rules on employers. After suitable action has been taken, Wood suggests that the handicap code might be used to identify residual discrepancies.

These proposed uses of the IDH codes clearly require that users will possess or acquire sufficient expertise to assign impairment, disability or handicap states accurately. While one is prepared to wait on events to see what difficulties are reported, it must be said that parts of the ICIDH manual are likely to seem forbidding to some potential users. The impairments classification will probably be most used without problems by medically or paramedically qualified professionals who have coped with the even more complex ICD for all their working lives. However, within the disabilities classification the supplementary gradings seem particularly complicated. Perhaps a shorter manual, copiously annotated with examples, could be prepared for those whose main interest is in this part of the classification? In addition, consideration might be given to formal trials of the use of all the classifications being set up as soon as possible. As an alternative, researches in which it is proposed to make a fairly extensive use of the classifications could be encouraged and monitored. For instance, the present author intends to use them to set up descriptions of disability and handicap states within current research into the assessment of such states by various professional and lay groups (Duckworth, 1980).

Social security assessment

The 'scientific' approach adopted for the WHO work seems likely to facilitate the acceptability of the proposals among scientists, medical and social, in many countries, if only because the paradigms and methods of science are fairly universal in the developed and developing world. However, in most countries, developed or not, the relatively uncontroversial theoretical approach of the scientist sometimes contrasts markedly with the very practical and pragmatic approaches characteristic of lawyers and administrators who have to draw up legislation regulating the systems for helping people with impairments, disabilities and handicaps in a practical way. Examples will, perhaps, make the point. To the scientist following the WHO scheme, disabilities are almost any deficits in the activities of everyday living which most persons can do as a matter of course. The administrator, however, is much more likely to seek a definition of disabilities within a more restricted but more immediately practical context: 'the reduction of the patient's ability as regards gainful employment' (WHO, 1958), for instance. That apparently very practical and useful definition was, in fact, suggested by an expert internationally-constituted committee, but the report discussing how it came to be formed points out that the committee immediately had to take note that in some countries, disability is taken to relate only to capacity for the work which the individual did before he became disabled. In other countries, disability related to capacity for any work, taking into account such factors as age, sex, education, occupation and the economic and social environment in which the person concerned had to live. Legal and administrative conceptualisations of disability, therefore, vary according to national, social and individual norms; they express the values implicit in the society within which they are formed.

Another example is provided by the British systems for assessing disablement for War and Industrial Pensions. The WHO committee making the observations mentioned above also pointed out that the medical principles on which assessment of disablement takes place do not vary much from one country to another. (Kessler (1970), has drawn attention to the way in which the Californian Industrial Injury schedules in use before the first World War were based on those of Imperial Russia in use in 1907! However, the Committee also held the view that the principles could only be usefully applied if account were taken of 'the occupational, social and economic background of those concerned' (Op. cit., p.8). Practical and political,and therefore value-laden, implications are paramount in legislation.

At the same time, within recent British Social Security legislation at least, there does seem a danger that the insights gained within the newer sciences into the status of different kinds of definitions and of methods of classification and assessment have not been taken into account or even enquired about. This may, of course, merely reflect the low status of the disciplines which study these topics in this country as contrasted with, in particular, the USA (Sharpe, 1975). But in Britain, as elsewhere, whenever an assessment of the abilities of pupils in schools or applicants for jobs is required, the measurement specialists are invariably consulted as to the status and scientific respectability of the measures used. Should it not also be so whenever the measurement of people's impairments, disabilities and handicaps is at issue?

The way ahead

At the time of writing (November, 1980), the WHO International Classification of Impairments, Disabilities, and Handicaps has been available for general

perusal for only about five months. There has therefore been little public comment on the manual and no critical review articles in the medical press. Perhaps the emphasis on its publication for trial use only as much as its evident overall merit has subdued criticism. The mere availability of the three classifications and the international and interdisciplinary agreement they represent, underlines the substantial progress that Wood and his colleagues have made in recent years. This study has therefore emphasized the potential utility of these classifications. Their development and refinement, their integration with the extensive work being undertaken on the development of health status indices of various kinds, and a thorough exploration of their applications in all branches of the health service and beyond is the obvious next step.

Appendix Definitions and characteristics of key terms in the ICIDH (WHO, 1980)

Impairment

Definition

In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function

(Note : ''Impairment'' is more inclusive than ''disorder'' in that it covers losses - e.g., the loss of a leg is an impairment, but not a disorder)

Characteristics

Impairment is characterized by losses or abnormalities that may be temporary or permanent, and that include the existence or occurrence of an anomaly, defect or loss in a limb, organ, tissue, or other structure of the body, including the systems of mental function. Impairment represents exteriorization of a pathological state, and in principle it reflects disturbances at the level of the organ

Disability

Definition

In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Characteristics

Disability is characterized by excesses or deficiencies of customarily expected activity performance and behavioural, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive. Disabilities may arise as a direct consequence of impairment or as a response by the individual, particularly psychologically, to a physical, senosry, or other impairment. Disability represents objectification of an impairment, and as such it reflects disturbances at the level of the person.

Disability is concerned with abilities, in the form of composite activities and behaviours, that are generally accepted as essential components of everyday life. Examples include disturbances in behaving in an appropriate manner, in personal care (such as exretory control and the ability to wash and feed oneself), in the performance of other activities of daily living, and in locomotor activities (such as the ability to walk)

Handicap

Definition

In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Characteristics

Handicap is concerned with the value attached to an individual's situation or experience when in departs from the norm. It is characterized by a discordance between the individual's performance or status and the expectations of the individual himself or of the particular group of which he is a member. Handicap thus represents socialization of an impairment or disability, and as such it reflects the consequences for the individual - cultural, social, economic, and enviromental - that stem from the presence of impairment and disability.

Disadvantage arises from failure or inability to conform to the expectations or norms of the individual's universe. Handicap thus occurs when there is interference with the ability to sustain what might be designated as ''survival roles''.

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